Continuous Commitment: Registered nurses in long-term care experience communicating with residents and their families about end-of-life care preferences

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"*If I have seen further*, *it is by* standing *on the shoulders of giants*."
- Sir Isaac Newton

Dedication

This dissertation and all the work that went before it are dedicated to the nurses I have been privileged and honored to work with over the years, particularly those working in long-term care facilities. Their dedication, advocacy and compassion for the individuals in their care inspires my research and teaching. I hope this dissertation does justice to their work.

To my wife Mary, you are a spark of light for me and so many others through your life of service. You have been and continue to be my first and most steadfast supporter, my editor and wise counsel, my strength. I could not have done this without you.

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Abstract

This dissertation begins with an introduction to the current state of the science in nursing research regarding long-term care (LTC) registered nurses' communication with residents regarding their end-of-life (EOL) care preferences. In LTC registered nurses lead care planning and evidence suggests residents, their families and nurses all benefit from engaging in EOL care communication, but systemic and individual barriers and obstacles impede it. With a large and growing population of older adult residents in U.S. LTC facilities, most of whom have not articulated their EOL care preferences, there is a pressing need to understand LTC registered nurses' EOL care communication strategies and facilitators. Three manuscripts are presented. The first reviews the literature regarding EOL care communication in LTC, finding there is a gap in nursing research about registered nurses' experientially-derived knowledge. These findings led to the design of an interpretive phenomenological interview study of LTC registered nurses' EOL care communication experience. The second manuscript presents insights from an innovative application of video conferencing technology to permit virtual, remote qualitative research data gathering during the novel coronavirus (COVID-19) pandemic. The third manuscript presents thematic and conceptual findings from a phenomenological interview study of 10 LTC registered nurses describing their EOL care communication process with residents and families. Finally, the body of aggregated work is synthesized, and implications for LTC organizational policy, nursing education, research and practice are noted.

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List of Abbreviations

ACP	Advance Care Planning
EOL	End-of-life
CINAHL	Cumulative Index of Nursing and Allied Health Literature
IRB	Institutional Review Board
LPN	Licensed Practical Nurse
LTC	Long-term care
PhD	Doctor of Philosophy
PRISMA	Preferred reporting items for systematic reviews and meta-analyses
RN	Registered nurse
THB	Parse's Theory of Humanbecoming
U.S.	United States

CHAPTER 1

Patient and family satisfaction with the quality and goal-concordance of end-of-life (EOL) care is associated with effective communication with healthcare professionals about the patient's EOL care preferences (Gilissen et al., 2017; White & Coyne, 2011). Effective communication about EOL care and the probability of goal-concordant patient care are also are associated with nurse job satisfaction and resiliency (Karlsson et al., 2017; Reinke et al., 2010; Strang et al., 2014; Towsley et al., 2015). Advance care planning (ACP) documentation is often used as a proxy for measuring the efficacy of EOL care communication (Sudore et al., 2017; Walczak et al., 2016). However, the need for in-depth communication about EOL care preferences between healthcare professionals, patients and their families is unlikely to be met by advance directives alone (Narang et al., 2015). Seriously ill patients and their families lack EOL care communication skills, experience with complex medical decision-making, and comprehension about their condition and prognosis (Bernacki & Block, 2014; Rao et al., 2014; Walczak et al.).

Currently, there are 2.1 million older adults residing in U.S. LTC facilities and this population is expected to grow significantly in the next ten years (Centers for Disease Control and Prevention, 2016). However, the majority of adults being admitted as new residents to LTC facilities have not engaged in EOL care planning discussions with their family members or healthcare professionals (Centers for Disease Control and Prevention). It is estimated that less than 50% of LTC residents have completed an ACP document to guide their EOL care and communicate their preferences (Wenger et al.,

2013). As LTC residents approach the end of their life, alignment between the EOL care they receive and their goals and values is influenced by the depth of understanding that LTC staff have about residents' individual EOL care preferences and choices (Mayahara et al., 2018).

In LTC settings, registered nurses lead resident care planning and management, not medical providers (Hanson & Henderson, 2000). As the communication nexus for LTC residents, their families, other staff and external providers, registered nurses take on the responsibility for ACP and EOL care planning, overcoming barriers and lack of education about EOL care communication (O'Conner-Von & Bennett, 2020; Towsley et al., 2015; van Soest-Poortvliet et al., 2015). Nurses in LTC form trust-based, close relationships with residents and their families or surrogates from admission to discharge or death (Dinç & Gastmans, 2013; Strang et al., 2014; Walczak et al., 2016). These close relationships help LTC nurses initiate and sustain EOL care discussions, understand residents' goals and preferences, and support resident's decision-making as their disease progresses and health declines (O'Conner-Von & Bennett). To advocate effectively for residents' goal-concordant EOL care, experienced LTC nurses recognize the necessity of a continuous EOL care communication process with residents and families, beginning at admission (Hov et al., 2009; Jeong et al., 2011) However, there is a gap between the need for ongoing EOL care communication and LTC nurses' capacity to initiate or sustain it (Gilissen et al., 2017). This communication gap has significant consequences for all stakeholders in LTC, negatively impacting residents' goal-concordant care, satisfaction

with EOL care and nurses' resiliency (Hickman et al., 2019; Kaasalainen et al., 2007; Kupeli et al., 2016; Midtbust et al., 2018).

Chapter 2 presents a critical review of the literature describing the experiences of LTC nurses with EOL care communication. Though qualitative research studies of registered nurses' experience communicating with patients and their families about EOL care preferences have been reported for acute and community care settings, there are none in the literature for LTC (Efstathiou & Walker, 2014; Gilstrap & White, 2014; Peden-McAlpine et al., 2015; Reinke et al., 2010; Shannon et al., 2011; Strang et al., 2014; Weigel et al., 2007). Despite LTC registered nurses' leadership role in resident communication and care planning, only one study in the literature focused on their experience with residents' EOL care and it did not specifically address communication (Emilsdóttir et al., 2011). Though registered nurses acquire knowledge and insights into effective EOL care communication through cumulative clinical experience (O'Conner-Von & Bennett, 2020), the paucity of literature about this important aspect of care planning and management in LTC suggests their experiential knowledge has not been disseminated.

This gap in the literature of nursing knowledge led to the design of a qualitative research study to describe LTC registered nurses' experiential knowledge about EOL care communication. The initial study design was an in-person phenomenological interview study, proposed in the winter of 2020 and submitted for approval. While the approval process was pending, the COVID-19 coronavirus pandemic began, significantly impacting LTC nurses, residents and families. In-person research with healthcare

professionals, including LTC registered nurses, was immediately suspended due to public health and institutional research restrictions to ensure their safety and wellbeing during the COVID-19 coronavirus pandemic. This unforeseen development necessitated adaptation of the study's research method to employ videoconferencing software technology for virtual, or remote interviews with LTC registered nurses. Chapter 3 presents an overview of this innovative qualitative research method which permitted the collection of real-time phenomenological data about EOL care communication from LTC registered nurses during the COVID-19 pandemic, while also adhering to public health and institutional research guidelines and contact restrictions. The overview of this method in Chapter 3 includes participant observations about the differences and similarities between virtual and in-person interviews, as well as the nursing researcher's insights gleaned about conducting virtual, or remote interviews as a qualitative research method.

Chapter 4 presents an interpretive phenomenological research study conducted to describe LTC registered nurses' experience communicating with residents and their families about EOL care preferences and choices. This study was designed to elucidate nurse participants' experiential knowledge and insights regarding effective EOL care communication with residents and families. Describing this phenomenon is a step towards a conceptualization of the elements of the complex, dynamic, longitudinal process of nurse-patient communication in LTC, which may help guide future research to evaluate EOL care communication interventions and education for registered nurses. A purposive sample of 10 registered nurses with more than two years of LTC clinical experience in urban, suburban and rural Minnesota LTC facilities were virtually

interviewed via a videoconferencing software application. Textual data from transcriptions of their recorded interviews were thematically analyzed employing Parse's theory of Humanbecoming to explicate relevant concepts from participants' experiences with EOL care communication with residents and families. The results of this study indicate that LTC registered nurses commit to leading a continuous EOL care communication process, beginning with establishing a close relationship with residents and families, to assess and understand how they can advocate for and honor each resident's EOL care preferences, goals and values.

Chapter 5 synthesizes the knowledge gained from the entirety of the work and their contribution to the body of nursing knowledge about EOL care communication in LTC settings. Experienced registered nurses in LTC embrace their role and responsibility as leaders for EOL care communication and planning. They view EOL care communication as central to their purpose as compassionate, proactive advocates for residents. Registered nurses in LTC work diligently and creatively to overcome existing barriers and obstacles to ensure residents receive goal-concordant EOL care, investing in both relational and instrumental care with residents and families. They describe the deep, close relationships they form with residents and families over time as akin to caring for a family member. These relational bonds have the benefit of facilitating mutual comprehension and collaboration but carry a cost to the nurses' wellbeing from the affects of their resident relationships during and after the resident's life in LTC.

Communication in LTC to discern and articulate residents' EOL care preferences is complex, multicomponent and dynamic. Registered nurses in LTC developed

knowledge and skills with EOL care communication are experientially derived. They do not perceive their learned knowledge from pre- or post-licensure nursing education adequately prepares them for EOL care communication. Incorporating experienced registered nurses' expertise and knowledge about effective EOL care communication with residents and families into nursing education, clinical practice guidelines, organizational policy, workflow design and communication intervention design can promote resident-centered EOL care and nurses' resiliency.

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CHAPTER 2

End-Of-Life Care Communication in Long-Term Care Between Nurses, Older Adult Residents and Families: A Critical Review of Qualitative Research

Overview

Chapter 2 presents manuscript 1, a critical review of the current literature regarding nurses in LTC communication with residents and families about EOL care preferences employing a symbolic interactionism theoretical framework. The review found that nurses in LTC learn through experience to become proactive advocates in EOL care to ensure residents' goals of care are met. A gap in nursing research literature was identified regarding registered nurses in LTC knowledge about facilitators and strategies for leading EOL care communication with residents and their families to articulate and document residents' EOL care preferences.

This is an accepted manuscript to be published in the *Journal of Gerontological Nursing* and is reproduced in accordance with Healio's publication embargo guidelines; see Appendix I.

Chapter 2 Summary

Registered nurses in long-term care (LTC) are a critical nexus for end-of-life (EOL) care communication with older adult residents and their families. A critical review of 17 qualitative research studies examined nurses' experience with EOL care communication in LTC. The findings indicate that time, preparation, advocacy, organizational resources, and a continuous, relational approach support EOL care communication. Regulatory burdens, understaffing, workflow demands, family and organizational dysfunction, anxiety, depression impede EOL care communication. This review revealed a gap in the literature describing LTC registered nurses' unique perspective and knowledge regarding EOL care communication with residents and families. There is a current, pressing need to understand the facilitators LTC registered nurses use to overcome obstacles to effective EOL care communication. Future research could inform clinical practice guidelines and EOL care nursing education, enhancing LTC nurses' capacity to develop trust-based relationships and improving the efficacy of current EOL care communication interventions in LTC.

Introduction

Nurses in long-term care facilities (LTC) facilities are a critical nexus for communication about end-of-life (EOL) care planning and preferences due to their unique professional role, length and breadth of their relationships with older adult residents and their families (Towsley et al., 2015). Efficacious advance care planning interventions in LTC are associated with nurses' cumulative experience with and willingness to initiate these discussions, nurse job satisfaction and resiliency, residents' and families' satisfaction with the quality and goal-concordance of EOL care (Gilissen et al., 2017; Karlsson et al., 2017; Towsley et al.**).** Experienced LTC nurses need years of clinical practice to acquire sufficient EOL care communication experience and skills due to inadequate education and preparation (O'Conner-Von & Bennett, 2020). A current gap exists between LTC nurses' capacity to initiate or sustain EOL care discussions and the identified need for EOL care planning (Gilissen et al.). This EOL care communication gap has significant consequences for all stakeholders, negatively impacting older adult EOL care outcomes, patient and family satisfaction, nurses' work satisfaction and stress (Bernacki & Block, 2014; Karlsson et al.). Without effective EOL care planning communication, older adults in LTC may not be able to provide nurses clear guidance about their preferences. Without appropriate education, information, support, and EOL care planning conversations residents' families may be unable to make EOL care decisions for incapacitated residents.

For the purposes of this review, several terms were defined. Residents are defined as seriously ill older adults residing in LTC while living with at least one advanced stage

disease or multimorbidity frailty. Family is the social group, including surrogates, designated by the older adult to make their health care decisions if they became incapacitated. End-of-life refers to the timespan from weeks to years that older adults live in a state of declining health. Long-term care refers to temporary or permanent residential healthcare facilities, including skilled nursing, memory care, assisted living and older adult care homes. An operational definition of EOL care communication is an iterative, discursive, shared decision-making relational process to reach consensus about a resident's future care choices and preferences, informed by their values and goals.

Theoretical framework

Nurses in LTC form trust-based, close relationships with residents and families that facilitates EOL care planning communication over time between admission and discharge, or death (Strang et al., 2014). Nurses' and residents' relationship in LTC is unique, given that they may interact up to forty hours per week over months or even years, as compared to acute or community care settings. Due to their strong, close relational bonds, residents and nurses in LTC are affected by each other and reflect intra- and interpersonally on the meanings of their experiences. Given this distinctive relational context, symbolic interactionism was chosen as the theoretical framework for this review because it incorporates a reflective, intra- and interpersonal process of iterative meaning-making. This review drew on Blumer's (1986) symbolic interactionism three-fold premise: first, individuals act on an object based on the meaning they ascribe to it; second, meanings are individual yet identified and articulated through social interactions;

and third, meanings can and do change, modified and communicated through a process of individual experiences which influence subsequent encounters with that object.

Aim

There is a current, pressing need to understand the facilitators and process that experienced nurses in LTC use to overcome obstacles to initiating and sustaining EOL care communication. Explicating these facilitators and process will support the design of efficacious education interventions to improve EOL care communication and may increase the probability of satisfaction with and goal-concordance of EOL care. Qualitative research studies of nurse-patient EOL care communication have been reported in the literature for acute and community settings (Efstathiou, & Walker, 2014; Gilstrap, & White, 2014; Strang et al., 2014; Towsley et al., 2015). However, there is a lack of qualitative research reviews in the literature regarding the facilitators that nurses in LTC employ to initiate and sustain communication about EOL care preferences with residents or their families. Wallace et al.'s (2018) interpretive meta-synthesis of EOL care in LTC did not focus on communication. Thus, a critical review was undertaken to identify, evaluate and synthesize the thematic findings of extant qualitative studies of LTC nurses' experience initiating and sustaining EOL care discussions with residents and families. The research question for this critical review was, "What is the lived experience of registered nurses in long-term care facilities initiating and sustaining communication with residents and their families about the resident's end-of-life care preferences?"

Methods

Inclusion & exclusion criteria

The review's inclusion criteria included peer-reviewed, English language qualitative research studies that used phenomenological, grounded theory or ethnographic methodologies to describe LTC registered nurses' experience communicating with residents and their families about EOL care preferences. Excluded studies were those in the grey literature, quantitative methodologies, studies that did not include registered nurses, care settings other than LTC, and studies that did not employ nurse-resident communication to clarify and articulate residents' EOL care preferences. This critical review was limited to qualitative research studies that met the inclusion criteria above published between January 1, 2000 and December 31, 2019.

Search Strategy

A preliminary search of the Ovid-Medline and CINAHL databases for studies published in English language peer-reviewed journals was using the MeSH terms identified in Table 1. A literature search was conducted using Boolean search logic tools, yielding a total of 230 studies met the eligibility criteria. These database searches were supplemented by hand searching, which added two studies that met the inclusion criteria. The Cochrane Library database was also searched but not identify any additional studies that met the inclusion criteria.

Table 1 - Medline MeSH Search Strategy

Database: Ovid MEDLINE and Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R) <January 1, 2000 to December 31, 2019>
Search Strategy:
---
1 exp Communication/ (293134)
2 exp Assisted Living Facilities/ or exp Housing for the Elderly/ (2845)
3 exp Homes for the Aged/ (13390)
4 exp Long-Term Care/ (25200)
5 exp Nursing Homes/ (37916)
6 2 or 3 or 4 or 5 (65015)
7 (long term care* or assisted living or nursing home* or Home* for the Aged or memory care).mp. (79938)
8 6 or 7 (83899)
9 communicat*.mp. (392435)
10 1 or 9 (563951)
11 exp Terminal Care/ or exp Advance Directives/ or exp Decision Making/ or exp Palliative Care/ (276313)
12 exp Advance Care Planning/ (8770)
13 11 or 12 (276813)
14 (end of life or advance* directive* or advance* care plan* or terminal care or palliative care).mp. (93720)
15 13 or 14 (291698)
16 8 and 10 and 15 (861)
17 (nurse or nurses).mp. (331863)
18 16 and 17 (213)
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Quality appraisal process

The researchers' level of confidence in the coherence, adequacy, methodology and relevance of the included studies' aggregated findings was assessed using Lewin et al.'s (2015) GRADE-CERQual qualitative research appraisal tool in Table 2. No overall numeric score was computed in GRADE-CERQual but a subjective judgment was made regarding high, moderate or low overall confidence in the review's aggregated findings from all the included studies.

Table 2 - CERQual Qualitative Evidence Profile

Objective: To identify, review and synthesize qualitative research evidence on EOL care communication barriers and facilitators in long-term care facilities
Perspective: Nurses, patients and their families experience of EOL care planning
Included Studies: Focus groups, interviews and surveys regarding each stakeholder's experience of the communication process with others to clarify a patient's advance directives, EOL care preferences and goals of care

Level	Definition
High confidence	Highly likely that the review finding is a reasonable representation of the phenomenon of interest
Moderate confidence	Likely that the review finding is a reasonable representation of the phenomenon of interest
Low confidence	Possible that the review finding is a reasonable representation of the phenomenon of interest
Very low confidence	Not clear whether the review finding is a reasonable representation of the phenomenon of interest
Component	**Definition**
Methodological limitations	The extent to which there are problems in the design or conduct of the primary studies that contributed evidence to a review finding
Relevance	The extent to which the body of evidence from the primary studies supporting a review finding is applicable to the context (perspective or population, phenomenon of interest, setting) specified in the review question
Coherence	The extent to which the review finding is well grounded in data from the contributing primary studies and provides a convincing explanation for the patterns found in these data
Adequacy of data	An overall determination of the degree of richness and quantity of data supporting a review finding

Review Findings	Studies Contributing	Methodological Limitations Assessment	Relevance Assessment	Coherence Assessment	Adequacy Assessment	Overall Confidence Assessment	Judgement Explanation
1) **Communication** aided in EOL care by time, interprofessional collaboration, trust, rapport, mutual respect, continuity of care	1, 2, 5, 6, 7, 9, 13, 15, 17	Minor methodological limitations	Minor relevance limitations	Minor coherence limitations	Minor adequacy limitations	High confidence	High confidence due to no concerns about methodological limitations, relevance, coherence, and adequacy.
2) **Communication** impeded in EOL care by family or organizational dysfunction, workflow demands, understaffing	2, 3, 4, 7, 9, 11, 13, 14	Minor methodological limitations	Minor relevance limitations	Minor coherence limitations	Minor adequacy limitations	High confidence	High confidence due to no concerns about methodological limitations, relevance, coherence, and adequacy.
3) **Benefits and burdens**, personally & professionally, with EOL care communication	3, 4, 7, 10, 11, 13, 15, 17	Minor methodological limitations	Minor relevance limitations	Minor coherence limitations	Minor adequacy limitations	High confidence	High confidence due to no concerns about methodological limitations, relevance, coherence, and adequacy.
4) **Preparation, resources and organizational support** for nurses are key to perceived EOL care effectiveness	5, 6, 8, 10, 11, 12, 14, 16	Minor methodological limitations	Minor relevance limitations	Minor coherence limitations	Minor adequacy limitations	High confidence	High confidence due to no concerns about methodological limitations, relevance, coherence, and adequacy.
5) **Nurses become proactive advocates** with patients & families,	6, 7, 8, 10, 11	Minor methodological limitations	Minor relevance limitations	Moderate coherence limitations due most studies with little or no description, analysis of nurses' data	Moderate adequacy limitations due to only five studies offering data	Moderate confidence	Moderate confidence due to minor concerns about coherence, and adequacy of data
6) **Continuous, relational process** for EOL care communication	7, 8, 10, 13, 15	Minor methodological limitations	Minor relevance limitations	Moderate coherence limitations due most studies with little or no description, analysis of nurses' data	Moderate adequacy limitations due to only five studies offering data	Moderate confidence	Moderate confidence due to minor concerns about coherence and adequacy of data

Note: Lewin, S., Glenton, C., Munthe-Kaas, H., Carlsen, B., Colvin, C. J., Gülmezoglu, M., ... & Rashidian, A. (2015). Using qualitative evidence in decision making for health and social interventions: An approach to assess confidence in findings from qualitative evidence syntheses (GRADE-CERQual). *PLoS Medicine*, *12*(10), e100

Results

Study Selection

Abstracts from the database searches were reviewed using the inclusion criteria. After removing duplicate records, the remaining records were reviewed by the researchers, comparing their study methodology, sample characteristics and abstracts against the inclusion criteria. A full text review of the studies that met the inclusion

criteria was conducted by the primary researcher. Seventeen studies were included because they met all the inclusion criteria for LTC registered nurses' experience communicating with residents and families about EOL care preferences. The PRISMA flowchart of included and excluded studies for this review is presented in Figure 1 (Moher et al., 2009).

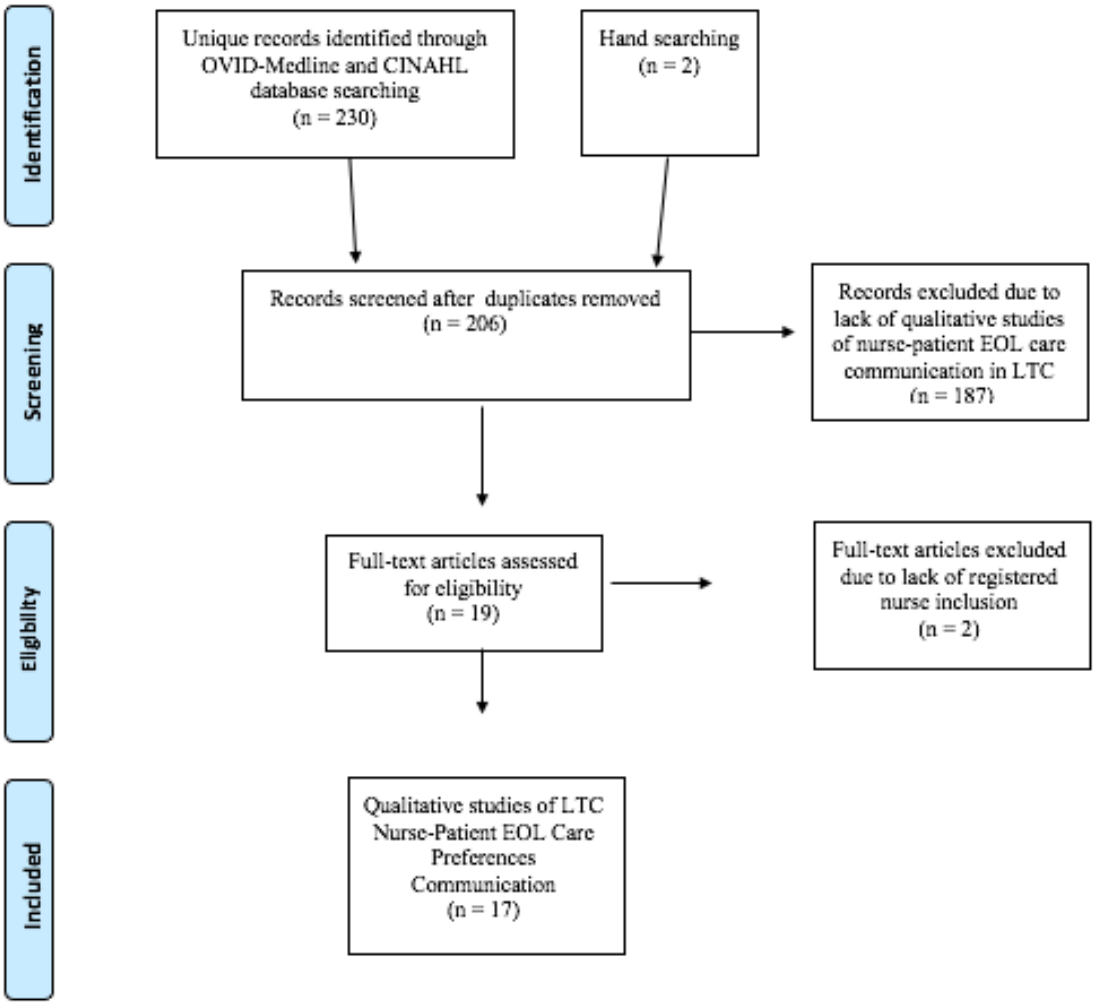

Figure 1 - PRISMA flowchart of included and excluded studies

Appraisal of quality

An overall assessment of confidence was made for the six aggregated findings of the included studies employing Lewin et al.'s (2015) GRADE-CERQual qualitative research appraisal tool in Table 2.

Data Extraction

Each included study's full text was reviewed and relevant data extracted by the primary researcher, including title, author(s), country of origin, qualitative methodology, sample size and characteristics, theoretical framework, thematic or category results and conclusions. Included studies' data were divided into Tables 3 and 4 to reflect differences in their sample characteristics. The sample populations for the five studies in Table 3 included only registered nurses (RNs) and licensed practical nurses (LPNs). The sample populations for the twelve studies in Table 4 included RNs, LPNs, certified nurse's aides, physicians and other LTC staff. Though LPNs do not have the same level of education or scope of practice as RNs, they play a significant role in supporting RNs' work educating, communicating and collaborating with residents and their families, which warranted grouping them together in Table 3. The data extracted from the 12 studies in Table 4 focused on their findings pertaining to LTC nurses' EOL care communication experience.

Only four studies in Tables 3 and 4 expressly grounded their research in theory, a weakness given that theoretical frameworks are the interpretative lens through which qualitative researchers analyze participant data in phenomenological, ethnographic and grounded theory studies. The theoretical models represented included realism (Kupeli. et

al., 2016), Goffman's dramaturgical model of social interaction (Oliver et al., 2006), interpretive constructionism (Walter, 2017), and symbolic interactionism (Funk et al., 2018). The included studies represent a broad geographic range of eight countries on three continents. A total of 324 nurses were included in the studies' samples, with a range from N = 3 to 106. The 11 studies that reported their sample population's gender and experience were predominantly female, ranging from 77% to 100%, with an average of twelve years' LTC experience. Five studies in Table 4 did not provide sample information about participants' age, gender or staff role, limiting their transparency and their findings' dependability (Bauer et al., 2014; Cable-Williams, & Wilson, 2017; Hanson, & Henderson, 2000; Majerovitz et al., 2009; Oliver et al., 2006). Only four studies focused on EOL care communication in LTC (Majerovitz et al.; van Soest-Poortvliet et al., 2015; Walter, 2017; Ward-Griffin et al., 2003). Most included studies described LTC nurses' EOL care experience, which encompassed but was not limited to communication with residents and their families (Andersson et al., 2018; Bauer et al.; Cable-Williams, & Wilson; Cagle et al., 2017; Emilsdóttir, & Gústafsdóttir, 2011; Funk et al.; Hanson, & Henderson; Kaasalainen et al., 2007; Kupeli. et al., 2016; Lopez, 2007; Midtbust et al., 2018; Oliver, et al.).

Table 3 - RN & LPN Perspectives

#	Study	Author, (Year), Country	Methodology	Study Aim	Theoretical Basis	Sample Characteristics	Themes, Concepts	Conclusions
1	End of life in an Icelandic nursing home: An ethnographic study.	Emilsdóttir et al. (2011), Iceland	Ethnographic observation, phenomenological focus group & interviews with 11 RN's at 1 LTC facility	Examine EOL care for elderly patients in an Icelandic nursing home	None Provided	None provided (Iceland has few LTC facilities. Details would impinge confidentiality)	1) Palliative care most important element of patient care in LTC: Death is a natural part of life; Advance directive discussions need to be timely; Dying peacefully with dignity is important to patient, family, nurses, staff 2) RN's in LTC: pillars of palliative care, evaluate timing for starting EOL care, attend patients' EOL care needs, support family	"The worlds of the living and the dying meet at the nursing home." RNs' professional knowledge contributes significantly to desirable EOL care of elderly patients in LTC
2	Caring about dying persons and their families: Interpretation, practice and emotional labor	Funk et al. (2018), Canada	Inductive, interpretative phenomenological interviews with 14 RN's & 12 nursing aides in LTC facility	Explore how nurses in LTC interpret and respond to emotional needs of dying patients and their families	Symbolic Interaction-ism	77% female Age Range: 19-59 yrs. Experience Range: 3-33 yrs. Work Range: 24-40 hours/week	1) Demonstrate "caring about" dying patients & families by being friendly and cheerful, calm, present, honest, trustworthy, and having a deep, almost spiritual connection 2) LTC nurses' moral belief re: importance of progression through Kubler-Ross grief stages 3) Emotional support facilitated by palliative care 4) Nurses' emotional support barriers: time, organizational culture, inconsistent care, under staffing	Nurses who can accurately interpret, assess and meet individual emotional needs may produce meaningful social interactions in residential care.
3	Suffering and Dying Nursing Home Residents: Nurses' Perceptions of the Role of Family Members	Lopez, R. P. (2007), U.S. A.	Inductive, interpretative phenomenological interviews with 3 RN's, 6 LPN's at 3 LTC facilities	Understand LTC nurses' perceptions of, and responses to residents' suffering near EOL	None Provided	100% female Avg. Age: 43 yrs. Avg. Experience: 16.8 yrs. Work Range: 20-40 hours/week	1) 3 types of LTC patient suffering: physical, psychosocial, existential. 2) Patients suffer when family in conflict about care, cannot not access palliative care in time, endure painful medical treatment 3) Patients' suffering has a strong impact on LTC nurses 4) Nurses often feel powerless to intervene to decrease patient's suffering	As primary clinician in LTC, nurses are on the front lines of suffering. Nurses perceive family as intimately involved in patients' suffering near EOL, either comforting or increasing patients suffering
4	Perceived barriers and facilitators in providing palliative care for people with severe dementia: the healthcare professionals' experiences	Midtbust et al. (2018) Norway	Qualitative descriptive focus group study & individual interviews with 14 RN's, 6 LPN's at 4 LTC facilities,	Examine LTC nurses' experiences of potential barriers and facilitators in providing palliative care for patients with severe dementia	None Provided	100% female Avg. Age: 44 yrs. Avg. Experience: 18 yrs.	1) Extensive temporary nursing & physician staffing threaten continuity and competence in palliative dementia care in LTC 2) Scarce resources, workflow demands affect weakest dementia patients. Nurses unable to provide effective care until very end of life 3) Nurses' moral distress, guilty conscience from conflict of increased EOL patient care needs and pressure to help every patient 4) LTC practice standardization weakens nurses' clinical autonomy, increases feelings of powerlessness, system overrides nurses' care knowledge and assessments	LTC facilities not sufficiently adapted to dementia patients' and their families' needs. Increasing the competence and proportion of permanent employees, preventing burdensome EOL transitions can improve continuity and quality of EOL dementia care in LTC
5	Long-Term Care Nurses' Perceptions Of Factors That Influence Their End-Of-Life Discussions With Surrogate Decision Makers	Walter, D. (2017), U.S. A.	Mixed-method online survey study of 21 RN's & 9 LPN's	Describe LTC nurses' perceptions of support needed and factors influencing communication with EOL surrogate decision makers	Interpretive construction ism	87% female Avg. Age: 45.6 yrs. Avg. Experience: 16.6 yrs. Work: 93% worked 40 hours/week	1) Surrogate characteristics impact communication, 2) Interdisciplinary team agreement, a peaceful environment and strong trust bonds between nurse, patient and surrogate are all crucial to EOL care communication 3) Nurses often too close to situation to see patient's wishes, need to create emotional distance 4) Advance care planning and living wills are useful as communication roadmaps	Walter's End-of-Life Transactional Communication Model proposes LTC nurse-surrogate EOL care communication influenced by surrogate characteristics, context, nurses' personal factors and situational inputs

Legend: EOL: End of Life; LPN: Licensed Practical Nurse; LTC: Long-Term Care; RN: Registered Nurse

Table 4 - Multiple Staff Perspectives

Study #	Study Title	Author, (Year), Country	Methodology	Sample	Study Aim	Theoretical Basis	Themes, Concepts	Conclusions
6	Care professional's experiences about using Liverpool Care Pathway in end-of-life care in residential care homes.	Andersson et al. (2018), Sweden	Qualitative descriptive focus group study and interviews with 9 RN's, 10 LPN's, and 5 M.D.'s at 10 LTC facilities	Nurses: 95% female Avg. Age: 50.3 yrs. Experience: 53% ≥ 10 yrs. M.D.'s: 60% female Avg. Age: 55.6 yrs. Experience: 100% ≥ 10 yrs.	Describe care professionals' experiences of using the Liverpool Care Pathway for the Dying Patient in the care of dying residents in 10 residential care homes	None Provided	Liverpool Care Pathway has supported clinicians: 1) Becoming more confident through interdisciplinary, structured approach to patient EOL care 2) Being supported to tailor patient-centered care to individual needs 3) Being supported to involve family in EOL decision-making and care 4) Becoming aware of the care environment	The Liverpool Care Pathway might be a useful tool for care professionals in improving end-of-life care in RCHs through increased attention to the goals of care, the individual needs of residents and family members involvement.
7	Staff–family relationships in residential aged care facilities: The views of residents' family members and care staff	Bauer et al. (2014), Australia	Qualitative descriptive focus group study and interviews with 5 RN's, 7 LPN's, 8 CNA's, 4 staff and 14 family members at 5 LTC facilities	None provided	Describe nurse, staff and family perceptions of staff–family role, constructive relationships and conflict in LTC facilities	None provided	1) Nurses identified communication as overarching category for constructive, collaborative, harmonious family relationships 2) 3 relationship themes: (a) building mutual trust, (b) nurses supporting family involvement, (c) nurses and staff keeping the family happy 3) Conflict arises for nurses from families' unrealistic or unmet expectations, and divergent views about patient care plans	Good communication, building trust both necessary for constructive relationships between staff and family in LTC. Mutual respect & cooperation support trust. Family's role within Australian LTC remains complex, ambiguous, are crucial
8	Dying and death within the culture of long-term care facilities in Canada	Cable-Williams et al. (2017), Canada	Ethnographic observation, focus group study and interviews with 3 RN's, 6 LPN's, 8 CNA's, 13 staff and 12 family members at 5 LTC facilities	None provided	Identify cultural influences on awareness of EOL, palliative care initiation for patients ≥ 85 years in Canadian LTC facilities	None provided	For nurses and staff, cultural influences on awareness of impending death and consequent initiation of a palliative care are: 1) Nursing & staff acting as resources, available to meet demands in LTC facilities 2) Belief that long-term care facilities are for living, not dying 3) Nurses belief that no one should die in pain 4) Nurses belief that no one should die alone	Late introduction of palliative care in Canadian LTC a consequence of multiple factors; cultural beliefs about LTC role, acceptable care, acknowledging dying, low staff-to-resident ratio and reduced staff preparation for palliative care
9	Caring for dying patients in the nursing home: Voices from frontline nursing home staff	Cagle et al., (2017), U.S.A.	Qualitative open-ended survey study with 106 RN's, 212 LPN's, 282 CNA's and 26 staff at 52 LTC facilities	93% female Avg. Age: 42% ≥ 31 and ≤ 50 yrs. Experience: 53% ≥ 5 yrs.	Describe nurses positive & negative experiences related to caring for dying patients	None provided	1) Nurses' positive experiences: creating close bonds with patients, good patient care, hospice involvement, being prepared for patients' death and good communication. 2) Nurses' negative experiences: challenging aspects of patient care, unacknowledged death, feeling helpless as a nurse, uncertainty, absent family, painful personal emotions, family discord	LTC nurses, staff form close, emotional ties with patients and families, grieve and struggle to cope with multiple patient deaths. Need to improve communication, patient support, hospice coordination and staff knowledge
10	Care of the dying in long-term care settings.	Harrison et al. (2000), U.S.A.	Qualitative descriptive focus group study with 77 total staff, including RN's, LPN's, CNA's, MD's at 2 LTC facilities	None provided	Describe how patients die in LTC, difference between "good death" vs. "bad death" and what LTC staff can do to help ensure patients die a good death	None provided	1) Nurses are EOL care leaders in LTC setting rather than MD's 2) Nurses face chronic lack of resources, regulatory intensity, burden of LTC's negative public image 2) A "good death" in LTC: appropriate ethical decision-making, good symptom management, emotional and spiritual preparation 3) Clinicians' roles during patients' EOL: surrogate family to some patients due to longitudinal caring relationship, responsible advocates for patients, interprofessional teamwork & skills to ensure good death, feeling helpless at times	Clinicians in LTC need EOL care preparation for their role within their team, especially nurses. LTC facilities can be site of good care during EOL care. Roles of all LTC staff need support, meaningful training, respect for each person's contribution, improved working conditions,
11	Nurses' perceptions around providing palliative care for long-term care residents with dementia	Kassalainen et al., (2007), Canada	Qualitative descriptive focus group study with 7 RN's, 14 LPN's, 1 nurse practitioner and 12 CNA's at 3 LTC facilities	100% female Avg. Age: 50 yrs. Avg. Experience: 11 yrs.	Describe current palliative care practices, challenges, knowledge & practice gaps, needs and decision making for dementia patients	None Provided	Nurses' dementia palliative care for a "good death": 1) Ongoing appraisals of patient deterioration (a primary indicator for palliative care), managing aggression, confusion, anxiety and pain 2) Family: education for palliative care & pain management, facilitating, reassuring & supporting family participation 3) Self-care: wanting to "be there" with patients, taking time to grieve alongside family. 4) Barriers: no time, insufficient education, lack of provider collaboration inconsistent & insufficient staffing	LTC nursing staff aim to facilitate a "good death" for dementia residents, innovatively & creatively managing multiple demands and care environment issues with limited resources and increased workload demands

Legend: ACP: Advance Care Planning; CNA: Certified Nursing Assistant; EOL: End of Life; LPN: Licensed Practical Nurse; LTC: Long-Term Care; MD: Medical Doctor; RN: Registered Nurse

Table 4 continued - Multiple Staff Perspectives

12	"We have no crystal ball" - advance care planning at nursing homes from the perspective of nurses and physicians	Kastbom et al. (2019), Sweden	Qualitative descriptive interview study with 9 RN's, 10 MD's at 9 LTC facilities	Nurses: 82% female Avg. Age: 44 yrs. Experience: 13 yrs. M.D.'s:71% female Avg. Age: 45 yrs. Experience: 15 yrs.	Investigate nurse's and MD's perspectives on factors that shape the process of ACP in a nursing home context	None Provided	1) Clinicians explore EOL care issues, restrictions & preferences with patients, with sensitivity to patient's readiness 2) Integrating patient's EOL preferences staff & family views into ACP 3) EHR documentation of patient's ACP decisions 4) Nurses' implementation & re-evaluation of patient's ACP to confirm EHR content of EOL plan One latent theme: clinicians seek to establish their beneficence to defend against maleficence accusations	Important to involve patients, family and clinicians in ACP process in LTC. Clear medical record documentation and proficiency in EOL communication related to ACP for MD's and nurses crucial to success
13	Context, mechanisms and outcomes in end of life care for people with advanced dementia	Kupeli et al. (2016), U. K.	Interactive, interpretive qualitative interviews 5 RN's, 3 LPN's, and 6 staff at multiple LTC facilities	86% female, Experience range: 6 mos. - 15 yrs.	Explore context, mechanisms & outcomes to provide good palliative care to advanced dementia patients in U.K. LTC facilities	Realism: context, mechanism & outcome	Good palliative care for advanced dementia patients prioritizes psychosocial & spiritual care, developing family relationships, symptom management and continuous, integrated care by multidisciplinary teams. Contextual factors that detract from good EOL care: financial efficiency emphasis, complex, bureaucratic health & social care systems, societal & family attitudes towards LTC staff, staff training & experience, complexity of dementia. Mechanisms for quality of EOL care: LTC staff confidence, family support and clarity about EOL care, EOL care resources, dementia specific palliative care	Contextual factors in LTC environment may be stubborn and negatively impact EOL dementia care. Improvements could come through local mechanisms. Systemic changes in LTC necessary for consistent, equitable, sustainable high quality EOL dementia care
14	We're on the same side: Improving communicatio n between nursing home and family	Majerovitz et al. (2009), U.S.A.	Mixed-method focus group and survey study of 71 RN's & 52 LPN's 323 CNA's at 26 LTC facilities	None provided	Identify multiple barriers to good communication associated with LTC nursing staff and family caregivers	None provided	1) Nurses value consultation before changes, trusting, respectful relationships with supervisors and families, support in addressing racist or abusive family comments, adequate staffing, teamwork 2) LTC institutional barriers: understaffing, nurse turnover, inadequate nurse training, medical model policies, rigid routines, poor interprofessional communication, work schedules not coinciding with family visits.	Nursing can advocate for patient, help family understand value of their emotional support role, maintain connections between patient and loved ones outside LTC facility
15	Managing the secrets of dying backstage: The voices of nursing home staff	Oliver et al. (2006), U.S.A.	Interpretive qualitative interviews 5 RN's, 4 LPN's, 5 CNA's and 2 staff at 2 LTC facilities	None provided	Understand & expose LTC nursing staff experiences of EOL care & share their private reality of death in LTC using Goffman's model	Erving Goffman's Dramaturgical model of Social Interaction	Through socialization, communication, relationships, interactions and superstitions, nurses manage dying "backstage," away from public view of LTC. Though nurses feel successful, positive about their backstage performances, some are moving the secret of dying from backstage to the front. Hospice care introduction plays a critical role in changing the definition and visibility of EOL care in LTC, resulting in new performances and outcomes	Dying not formally acknowledged in LTC setting, yet nursing staff experience reality of death and informally responds to patients' special needs
16	Advance care planning in nursing home patients with dementia: A qualitative interview study among family and professional caregivers	van Soest-Poortvliet et al. (2015), Netherlands	Qualitative descriptive interviews with 20 family caregivers, 21 MD's and 24 nurses about 26 decedent dementia patients in 16 LTC facilities	Nurses: 92% female Avg. Age: 44 yrs. Avg. Experience: 20 yrs. M.D.'s: 67% female Avg. Age: 44 yrs. Avg. Experience: 15 yrs.	Describe family, MD's and nurses' perception of ACP process in LTC for dementia patients and explore factors influencing its timing, content	None provided	Factors that influence timing and content of ACP discussions and decisions for dementia patients: 1) MD's strategy of waiting for a patient's decline or change to initiate ACP discussions 2) Nurses take the initiative to proactively discuss EOL treatments, scenarios 3) Nurses & MD's learn patient & family wishes, assess family's willingness to make decisions, reach consensus and be involved in care planning 4) Nurses communicate continuously	ACP for LTC dementia patients influenced by multiple factors: LTC clinicians' characteristics, context, patient's condition and family. All factors modify the timing and content of ACP discussions and decisions
17	Relationships Between Families and Registered Nurses in Long-Term-Care Facilities: A Critical Analysis	Ward-Griffin et al. (2003), Canada	34 critical ethnographic interviews with dyads of 17 family caregivers and nurses caring for dementia patients in 1 LTC facility	Avg dyad relationship: 1.5 yrs. Nurses: 100% female Avg. Age: 44 yrs. Caregiver: 82% female Avg. Age: 65 yrs.	Critically examine relationships in dyads of family caregiver and registered nurse caring for LTC dementia patients	None provided	4 nurse-family relationship types: (a) collaborative, a family-centered approach to care, with family heavily involved, (b) carative, a family-centered approach to care, with family minimally involved, (c) competitive, a resident-focused approach to care, in which family is heavily involved, and (d) conventional, a resident-focused approach to care, in which family is minimally involved. Dyadic relationships built on mutual respect for knowledge and skills of both parties.	Nurses' time allotted to building relationships, plus their interprofessional and administrative support all key to initiating and sustaining family-centered care. Mentorship of younger nurses by experienced nurse leaders may help foster family-centered practices.

Legend: ACP: Advance Care Planning; CNA: Certified Nursing Assistant; EOL: End of Life; LPN: Licensed Practical Nurse; LTC: Long-Term Care; MD: Medical Doctor; RN: Registered Nurse

Discussion

The data were analyzed initially by the primary researcher and then reviewed by the secondary researchers. Communication was the overarching theme of the studies, explicating prognosis, expediting initiation of palliative care and symptom management, identifying residents' EOL care needs, and supporting resident-centered EOL care. Nurses develop close, trust-based bonds with residents and families in a continuous, relational process built from admission onwards (Funk et al., 2018). Communication facilitators in EOL care planning are adequate chronological and experiential time, presence and candor with residents and families, nursing competence, interdisciplinary teamwork, organizational flexibility, relational trust, continuity in care assignments and ongoing, timely assessments of evolving conditions and prognosis. Communication barriers in EOL care are regulatory and bureaucratic burdens, high nurse-resident ratios indicative of understaffing, unreasonable workflow demands, families' lack of knowledge of EOL care, lack of organizational support, lack of collaboration amongst stakeholders, anxiety, depression and the cumulative impact of grief on nurses from resident deaths.

Nurses in LTC strive to be proactive EOL care advocates for and with residents, yet they also express the need for ongoing education, resources and organizational support to become more effective EOL care advocates. Nurses in LTC experience personal and professional benefits from leading EOL care communication, including feelings of generativity, increased self-efficacy, growth, vocational satisfaction and they appreciate the unique benefit of longitudinal care relationships. Nurses also experience

burdens, including feelings of depletion and stress, caring for residents with complex needs, coping with discordant or absent families, moral and ethical distress, powerlessness and dissatisfaction with organizations that prioritize financial performance or undermine nurses' scope of practice.

From this analysis of the qualitative studies' data, five concepts and one construct were synthesized.

Concept: Communication

Communication was a primary enabler of goal-concordant EOL care, engendering comprehension and collaboration. "Communication was the core category supporting the formation of constructive relationships" (Bauer et al., 2014, p. 564). This review found fairly consistent descriptions of LTC nurses' EOL care communication facilitators and barriers. Some barriers to communication were unique to specific relationships. *"*Nurses perceived that residents suffered because family members interfered with their efforts to comfort the residents" (Lopez, 2007, p. 145). Other barriers were organizational or systemic, such as understaffing and workflow demands, "Residents in long-term care facilities are increasingly sick and need increasing amounts of help. However, resources do not increase as tasks progress" (Midtbust et al., 2018, p.4). Nurses identified interprofessional collaboration, time, and continuity in resident care assignments as facilitators for EOL care communication. "Nursing staff should have stable assignments to facilitate team building and to allow them to get to know residents" (Majerovitz et al. 2009, p.19).

Concept: Proactive Advocates

Nurses in LTC were the EOL care leaders in LTC, adopting a proactive role in palliative care symptom management and resident advocacy to ensure goal-concordant care. “RNs were the pillars of care for the dying elderly in the nursing home, …(they) played a crucial role in the analysis of impending deaths and proper responses to them. The registered nurses were usually the first people to realize that it was time to initiate end-of-life care” (Emilsdóttir & Gústafsdóttir, 2011, pp. 409-410).

Concept: Preparation, Resources & Organizational Support

With adequate time, education, preparation and organizational support, LTC nurses developed mutually respectful, trust-based relationships with residents and families, felt empowered to probe comprehension, communicated openly and compassionately with residents and families around EOL care planning. “When employees are appropriately supported, (they) accurately interpret, assess and meet individual emotional needs” (Funk et al., 2018, 525). The effects of organizational culture on EOL care communication was noted in multiple studies “Characteristics of the LTC setting influenced the dying experience” (Hanson & Henderson, 2000, p. 231).

Concept: Continuous, Relational Process

Communication about EOL care planning is a continuous, relational process, building trust with all stakeholders from admission onwards (Funk et al., 2018). Multiple studies observed that trust-based relationships develop and deepen EOL care communication. “Enhancing their trust and sense of security promotes reassurance, mitigates dissatisfaction and conflict, and facilitates sharing by patients and families”

(Funk et al., 2018, 523). “Staff members can, and do, form close affectionate ties with patients and families” (Cagle et al. 2017, p. 206).

Concept: Benefits & Burdens

EOL care and communication affects nurses personally and professionally (Karlsson et al., 2017). “They often described their relationships with certain residents similar to familial relationships, such as mother or grandmother… like a mother who nurtures a baby” (Lopez, 2007, p. 146). However, LTC nurses also experience additional stressors. “Nurses, like others who are faced with loss, need their grief acknowledged and adequate support provided to them so they can manage afterwards… LTC nurses are particularly vulnerable to moral distress and emotional burnout” (Kaasalainen et al., 2007, p. 179).

Construct: Time

In every study in this review, time was observed to be both a facilitator and barrier of EOL care communication. From these aggregated findings, time is inferred as a construct that moderates EOL care communication between LTC nurses, residents and their families. As a construct, time has two dimensions: chronological and experiential. Chronological time facilitates communication, measures prognosis and life expectancy, and fosters relational trust. Experiential time develops nurses’ communication skills, EOL care knowledge and capacity for presence and awareness. “Nurses’ attitudes have a tendency to change over time related to their death and dying experiences” (Walter, 2017, p. 33). When communication facilitators are operational, nurses perceive more time available to communicate with residents and families. “After a while, time goes on, and

you begin to think maybe there is more time than you thought" (Cable-Williams & Wilson, 2017, p. 6). Conversely, EOL care communication barriers lead to nurses perceiving less time available for communication. "When 'caring about' is not an organizational imperative (and when there is little time or space for this work), authentic emotional care may be more difficult to achieve" (Funk et al., 2018, p. 524). Future research may benefit from examining the effects of time in relation to LTC nurses' observations of EOL care communication facilitators and barriers.

Theoretical Application

Applying symbolic interactionism to this review's findings, LTC nurses observe the varied meanings residents and families bring to their lived EOL care experience, including meanings derived from close relationships, life purpose, anticipatory grief, existential and psychospiritual reflection, uncertainty, hope, gratitude, reconciliation and suffering. As a resident's health declines and mortality salience increases, these meanings change for all stakeholders. This review demonstrates that nurses in LTC are not only mediators of meaning as objective third-party facilitators, but also personally affected by EOL care's meaning–interaction process. These nurses reevaluate personal and professional meanings they ascribe to EOL care, including grief, loss, psychospiritual beliefs, as well as their vocational purpose, moral and ethical principles. Every person in the nurse-resident-family triad imbues EOL care communication with their own meanings, which evolve intra- and interpersonally through their interactions.

Implications for Nursing Research

Despite the positive association between LTC RNs' experience and efficacy of EOL care communication (Efstathiou, & Walker, 2014; Gilstrap, & White, 2014; Sharp et al., 2013), only two of the included studies' samples focused exclusively on LTC RNs (Emilsdóttir & Gústafsdóttir, 2011; Ward-Griffin et al., 2003). Thus, there is an indicated gap in nursing research knowledge about the strategies and facilitators they employ to overcome obstacles and facilitate EOL care communication with residents and families. Due to the complexity of the LTC EOL care communication process, developing knowledge and measuring the contributions of its individual components is challenging (Hickman et al. 2019). Describing the components and process employed by these nurses in future research would be a significant first step towards sequencing efficacious communication processes and measuring each component's relative contributions. Such research could benefit from applying qualitative research methodologies to elucidate factors that aid or impede nurses' relational processes to build rapport and trust with LTC residents and families, necessary for effective EOL care planning and documentation (Dinç & Gastmans, 2013; Strang et al., 2014). Employing an interpretive phenomenological interview methodology within a constructionist framework would permit a rich description of successful facilitators and strategies applied by LTC RNs with at least 2 years of LTC clinical practice experience. The outcome of this research could be used to improve the design and measurement of LTC EOL care communication interventions (Strang et al., 2014).

Implications for Nursing Practice

Nurses in LTC need adequate education, preparation and organizational support to communiicate with residents and families regarding EOL care planning and documentation. Specifically, improving interprofessional collaboration, allowing sufficient time for communication, and ensuring continuity in resident care assignments enhance LTC nurses' capacity to develop trust-based relationships. Advocating for residents in EOL care carries benefits and burdens for nurses. Encouraging their expression or articulation could promote self-care and resiliency for LTC nurses and improve work satisfaction. Explicating LTC nurses' EOL care communication process might accomplish quadruple-aim objectives for nursing practice: reducing utilization inconsistent with residents' goals of care, supporting nurses' job satisfaction and resiliency, improving goal-concordant outcomes and residents' satisfaction with EOL care.

Implications for Nursing Education

Most undergraduate and graduate nursing education programs include therapeutic communication skills and hospice education, but not all nurses in LTC perceive that their academic education prepares them to initiate or sustain EOL care communication as the primary nexus for communication and care planning (O'Conner-Von & Bennett, 2020). It is imperative that nursing education programs partner with practice professionals to create safe learning environments, while using evidence-based and innovative strategies such as end-of-life simulations to prepare nurses in the art and skill of EOL communication (Carman, et al., 2016; Isaacson & Minton, 2018; Ladd et al., 2013). In addition, established online and in-person EOL care education programs such as the End-

of-Life Nursing Education Consortium (ELNEC, n.d.) provide continuing education for LTC nurses to acquire the skills, resources and confidence to initiate and sustain EOL care communication with residents and their families.

Strengths and Limitations

The studies included in this review have several limitations. First, describing EOL care communication was the primary objective in only two studies, limiting the dependability of this review's aggregated findings to broader conclusions about LTC EOL care communication processes. Second, 12 studies' findings are based on the experiences of multiple LTC staff, limiting the confirmability and transferability of this review's aggregated findings to the population of LTC nurses. Third, 13 studies did not provide a theoretical framework through which their data were analyzed or conclusions drawn. This critical review process has several limitations. First, qualitative studies of nurses' EOL care experience in LTC settings are conducted and published by researchers in multiple, diverse disciplines, thus it is likely this review may have missed existing pertinent studies. Second, this review was limited to peer-reviewed published studies and does not include data from grey literature or unpublished studies.

Despite these limitations, this review possesses several strengths. First, its data are drawn from 17 qualitative research studies in eight countries, presenting a global body of data. Second, 11 studies were published in the last ten years, thus most of the findings represent recent research in EOL care communication in LTC settings. Third, the GRADE-CERQual critical appraisal tool was used to assess confidence in the studies' methodology, relevance, coherence and adequacy (Lewin et al., 2015).

Conclusions & Relevance

This review revealed a gap in nursing research literature regarding the unique perspective and knowledge of experienced LTC RNs in initiating and sustaining EOL care communication with residents and their families, indicating a need in the literature for knowledge about this phenomenon. The facilitators and barriers LTC nurses experience in EOL care communication were analyzed and summarized. With experience, nurses in LTC become proactive advocates for residents, leading EOL communication to ensure residents' goals of care are met. Ongoing EOL care communication results in professional and personal benefits and burdens for LTC nurses, and the quality of EOL care communication is affected by the organizational resources, support and education they receive. The construct of time was identified, with LTC nurses perceiving more or less of it available depending on the prominence of communication facilitators or barriers, respectively. Applying symbolic interactionism to this review's findings, the meanings LTC nurses, residents and families derive from communication about EOL care evolve over time. These findings are significant due to the current, pressing need to understand the facilitators and process that experienced LTC nurses use to overcome obstacles to effective EOL care communication. Future research could apply qualitative research methodologies to describe the EOL care communication factors that aid LTC RNs in building rapport with residents and families which could inform clinical practice guidelines and EOL care nursing education and enhance LTC nurses' capacity to develop trust-based relationships.

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CHAPTER 3

A Novel Application of Secure Videoconferencing Technology in a Study of Nurses' Communication About End-Of-Life Care

Overview

Chapter 3 presents manuscript 2, a synopsis of the implementation of a qualitative research study during the COVID-19 pandemic while adhering to public health and institutional research guidelines and contact restrictions. The results of Chapter 2, manuscript 1, suggested a gap in nursing knowledge regarding LTC registered nurses' communication with residents and families regarding EOL care preferences and planning. Ten long-term care registered nurses were individually interviewed virtually via a secure videoconferencing software application to gather phenomenological data about their EOL care communication experiences residents and families.

This manuscript has been submitted for publication.

Chapter 3 Summary

An innovative application of a videoconferencing software application permitted the collection of real-time qualitative research data during the COVID-19 pandemic while adhering to public health and institutional research guidelines and contact restrictions. Ten long-term care registered nurses, each with more than two years of clinical experience, described their EOL care communication experiences with residents and families. Participants were individually interviewed virtually using a secure videoconferencing application. Nurse participants were uniformly positive about the convenience, quality, interactivity and security of this method of data gathering, perceiving no difference between virtual and in-person interviews. Virtual, secure videoconferencing's benefits for qualitative research include immediacy, convenience, interactivity, safety and security, while also presenting challenges from internet instability and limited presence. Suggestions were offered for conducting future virtual nursing qualitative research. Gathering data via virtual videoconferencing could have a positive impact on the safety, convenience, security and immediacy of gathering data for nursing knowledge.

Introduction

Nursing research has been significantly restricted during the recent COVID-19 virus (COVID) pandemic in the United States to adhere to public health guidelines and mandates limiting physical contact and communication with nurses, patients and other healthcare professionals, restricting qualitative research such as in-person interviews to gather data. The gap between gathering timely information nursing science needs and conducting safe, secure research impacts nursing scientists' ability to generate knowledge, including about COVID's effects on nurses and their relationships with patients and families. Given the disproportionate impact of the COVID virus on older adults' health, this gap has consequences for gerontological nursing in long-term care (LTC) settings. Nursing scientists need to understand the COVID pandemic's effects on nurses and nursing in LTC to adapt and improve nursing education, policy and practice in preparation for future events.

Due to their role as a nexus for care management, planning and education, registered nurses in LTC settings are crucial to end-of-life (EOL) care communication, facilitating resident and family comprehension and communication about EOL care preferences to encourage collaboration on resident-centered, goal-concordant EOL care (Gilissen et al., 2017; O'Conner-Von & Bennett, 2020; Towsley et al., 2015). Experienced LTC nurses acknowledge the necessity of a continuous communication process with residents, families and surrogates to advocate for resident-centered goal-concordant EOL care (Hov et al., 2009; Towsley et al.). Prior to the COVID pandemic, nurses faced multiple barriers to initiating and sustaining EOL care communication,

including time constraints, lack of training and fragmented communication patterns (Karlsson et al., 2017; Towsley et al.). There is a gap between the need for EOL care planning communication in LTC and nurses' capacity to initiate or sustain it (Gilissen et al.,). This gap has significant consequences for all stakeholders in LTC, negatively impacting residents' quality of care, resident and family or surrogate satisfaction with EOL care and nurses' work satisfaction and resiliency (Hov et al.; Lund et al., 2015; O'Conner-Von & Bennett; Towsley et al.).

The pressing need to understand the facilitators and processes experienced LTC nurses use to initiate and sustain EOL care communication has become more acute due to the clinical, social and organizational effects of the COVID pandemic on nurses, residents and their families (Curtis et al., 2020). However, due to public health mandates regarding contact restrictions and isolation for residents, nurses and other staff in LTC, conducting in-person interviews with LTC nurses to gather timely, necessary data is not currently feasible. One novel solution to this dilemma is to conduct qualitative research individual interviews virtually, using secure videoconferencing software applications such as Zoom (2020).

Purpose: This paper discusses some of the benefits and challenges observed while conducting a qualitative research study with registered nurses in LTC virtually via a secure Zoom videoconferencing software application. Nurse participants were individually interviewed virtually to gather phenomenological data about their EOL care communication experiences residents and families. Though qualitative research in LTC has demonstrated feasibility of gathering evidence through in-person interviews with

nurses about EOL care (Hov et al., 2009; Touhy et al., 2005), none have focused on nurses' communication process and none have been conducted virtually.

Background

Residents in LTC and their families need timely, relevant information and support to comprehend the relative risks and benefits of the resident's EOL care options, and communicate their preferences (Towsley et al., 2015). Yet, they are reluctant to initiate EOL care discussions, waiting for healthcare professionals to initiate them (Gilissen et al., 2017). This problem has been exacerbated by communication and interaction restrictions for nurses, residents and families during the COVID pandemic (Curtis at al., 2020). Gerontological nursing in LTC settings during the COVID pandemic has been negatively impacted by increased resident morbidity and mortality, staff and resident virus infection and illness, fewer or virtual interprofessional support services, resident isolation and increased nursing workloads. At the same time, nurses in LTC must ensure residents receive mandated EOL care planning interventions, including discussion of advance care directives (Center for Medicare & Medicaid Services, 2017). However, it is estimated that less than 50% of the United States' 2.1 million LTC residents have completed advance directive documentation (Centers for Disease Control and Prevention, 2016).

Method

Design: This study employed an interpretive phenomenological qualitative research design, a systematic, intersubjective study of individuals making meaning from their lived experience (Laverty, 2003). Interpretive phenomenology was the appropriate

method for gathering data from LTC nurses on the dynamic reality of EOL care communication with residents and families, which evolve over time. Accessing LTC nurses' intent, motivation and meaning, through phenomenological interviews was crucial to understanding their processes to initiate and sustain EOL care communication and their developed knowledge to overcome extant obstacles to EOL care discussions with residents and families (O'Conner-Von & Bennett, 2020; Towsley et al., 2015).

Virtual Research: This study was an innovative application of virtual videoconferencing software application to conduct and record qualitative research interviews with LTC registered nurse participants. The use of virtual videoconferencing software application allows researchers to conduct participant interviews safely and securely, while adhering to public health guidelines and restrictions during the COVID pandemic and following institutional standards for human subject research and data privacy. Conducting virtual videoconferencing interviews permitted gathering real-time data about its impact on EOL care communication in LTC during the COVID pandemic. Virtual videoconferencing technology permitted each nurse participant greater flexibility in choosing the most convenient time and place to conduct their individual interview.

Feasibility: The researchers, all affiliated with the University of Minnesota School of Nursing, recently conducted a critical review of qualitative research studies of EOL care communication between nurses, older adult residents and their families in LTC (Bennett et al., *in press).* In 2019, two of the researchers conducted focus group study with 14 registered nurses in LTC regarding their communication strategies with older adult residents and their families about EOL care preferences (O'Conner-Von & Bennett,

2020). They found that LTC nurses used persistent, consistent communication with all stakeholders to advocate for goal-concordant EOL resident care, even though initiating and sustaining EOL care communication was challenging and exacting.

Initial demographic questions for participants to be completed before their interview
Your Age
Your Sex: M/F
Your Nursing Education: Associate: ___ Baccalaureate:___ Masters: ____
Your Nursing Education Institutions(s)
Your Total Nursing Experience (years)
Your Total LTC Nursing Experience (years): ___ SNF ___ TCU ___ Memory Care ___ ALF
Your Other Clinical RN Experience (years): ___ Acute ___ Rehab ___ Home ___ Clinic ___ Hospice
Your Workplace/Facility Setting: ___Urban __Rural __ Suburban
What do you remember learning about caring for patients approaching the end of life in your nursing education?
Where and when did you learn this?
What do you remember learning about communicating with patients and their families regarding end-of-life care in your nursing education?
Where and when did you learn this?
Briefly describe the amount and delivery of your continuing education on end-of-life care within your LTC workplace(s)? (i.e. – in-service, conferences, SharePoint, journals, web, etc.)

Interview Questions for Nurses in Long-Term Care: Experience with Patients & Families Communicating About End-Of-Life Care Preferences & Goals

1. I'm interested in hearing about your experiences in LTC communicating with over the entire time a patient is in your facility: weeks, months, even years. Think back to a recent experience that you had with a patient or family about end-of-life care discussions. Please describe it.
2. Please describe both a positive and negative experience with patients and families about end-of-life care discussions with and surrogates about end-of-life care preferences, and goals?
3. What have you found helps you know start, and keep these discussions going?
4. How do you know when you have discovered enough information about the patient's goals, preferences and values for an end-of-life care plan?
5. Please give an example, or two, of a time when you overcame obstacles to communicating with patients and families? What were the obstacles and how did you overcome them?
6. What advice would you have for new nurses just getting started in long-term care about communication with patients and families about end-of-life care preferences?
7. What have I not asked you about when it comes to communication with patients and families about end-of-life care preferences?

Figure 1 - Participant Interview and Demographic Survey Questions

Participants: The study used a purposive sample of volunteer registered nurse participants drawn from the population of English-speaking registered nurses with at least

2 years of LTC experience employed by a LTC organization with multiple facilities in the Upper Midwest. Based on O'Conner-Von & Bennett's (2020) and Peden-McAlpine et al.'s (2015) qualitative research individual interview studies about nurse-patient communication, it was estimated that a sample of 8-12 participants from a diverse LTC nurse population would be required to achieve data saturation. If necessary, additional eligible LTC nurses could be interviewed until saturation was achieved.

Recruitment: The study's recruitment and enrollment protocols and procedures were approved by the Institutional Review Board at the University of Minnesota. A private Minnesota-based LTC organization supported this study's participant recruitment and enrollment. To ensure participant safety and adhere to public health guidelines restricting in-perron interaction, eligible participants currently employed by this LTC organization were recruited by email with the support of the nursing leadership at each facility. Recruitment emphasized the study's potential research benefits: (1) the opportunity to explore and describe participant's EOL care communication experience; and (2) participant's insights and knowledge would be disseminated, contributing to the breadth and depth of LTC nursing knowledge and science. Eligible nurses who volunteered to participate were enrolled through email communication following study protocols. Communication with eligible participants included their acknowledgement of: (1) the study's purpose; (2) researchers' affiliation with the University of Minnesota School of Nursing; (3) protocols to assure participant confidentiality through de-identification procedures, data safety and secure data storage; (4) video recording of their interview; and (5) initial interview and demographic survey questions (Figure 1).

Data Collection

Each participant interview was conducted by the primary researcher following Van Manen's (1990) interpretive phenomenological interviewing guidelines using their lived experience descriptions to constitute the phenomenon and elucidate their experientially developed knowledge and attached meaning. To minimize participant burden, increase their safety, privacy and convenience, interviews were conducted virtually at a time chosen by the participant. To ensure every participant received the same informed consent and enrollment procedures, participants were notified prior to their interview by email and then verbally at its outset that their interview would be conducted and recorded on the University of Minnesota's secure Zoom (2020) videoconferencing software application. Participants also received an email communication from the primary researcher prior to their interview with: (1) an electronic calendar invitation with the date and time for their interview; (2) instructions for downloading the Zoom client software application; (3) the unique internet hyperlink, generated by the primary researcher, that enabled their device to access the secure interview; and (4) a summary of the study protocols, informed consent procedures and initial interview and demographic survey questions (Figure 1). Individual interviews took up to 90 minutes and followed interpretive phenomenological interviewing guidelines, with question prompts that focused the interview on the phenomena of interest (Rubin & Rubin, 2012). A modest financial incentive was offered to each participant by the primary researcher from personal funds at the end of their interview as a token of appreciation. All interview recordings were professionally transcribed by a private

contractor with substantial experience in transcribing videoconferencing interview recordings. For quality assurance, researchers reviewed interview transcriptions to verify their fidelity to the video recording. Interview data security and integrity were ensured by restricting access to recordings and transcripts to the researchers, and by following the University of Minnesota School of Nursing's institutional guidelines to protect data privacy in research studies.

Results

Ten registered nurse participants from an urban, suburban and rural LTC facility were electronically enrolled via email and individually interviewed via the University of Minnesota's Zoom (2020) videoconferencing software application. All participants acknowledged they approved recording their interview and none expressed reservations or concerns regarding data security during their interview or storage of its recording afterwards for transcription and analysis. Participants were enrolled until transcribed interview textual data and interviewer field notes indicated that sufficient data had been generated to achieve thematic saturation. Saturation was reached when participants' language content did not reveal any novel data. Each participant subsequently had an opportunity to review their interview transcription to offer feedback, clarify language and meaning, or stimulate additional contributions from their experience. In addition to interview questions regarding their experience communicating with residents and their families about EOL preferences and goals, each participant was asked about their experience participating in a virtual videoconferencing interview compared to an in-person interview.

Interview participants expressed positive reactions to conducting their individual interview virtually via Zoom's (2020) videoconferencing software application, almost preferring the virtual method for its convenience. Participants did not perceive any difference in visual or audio quality between virtual and in-person interviews. They observed that videoconferencing combined the immediacy and presence associated with in-person interviews with the convenience, security and safety of scheduling and conducting their interview at a time and place convenient for both their work and personal schedules. Four of the 10 participants chose to be interviewed in a non-work setting, most at home. Nurse participants' verbatim comments and observations regarding conducting their interview virtually via videoconferencing versus in-person are summarized in Table 1.

Table 1 – Participant comments on conducting an interview virtually via videoconferencing

Nurse Participant	Verbatim Participant Comments (line numbers from transcribed interview or email response)
2	"Honestly I do not feel that the Zoom format was any different. Perhaps that is because this is simply the world we live in now!" (email)
3	"I really liked the Zoom option though! It was very personal and felt authentic. I did not mind it at all." (email)
4	"No difference with in-person interview." (email)
5	"I don't think there's any difference, because I can see you. Well, if it's on the phone it's another thing, but if I can see you and you can see me, I don't see that it's much different, actually." (853-855)
6	"I like Zoom. Yeah, absolutely. I just did a beginning yoga online class [before this interview]." (785)
7	"No difference with in-person interview." (email)

8	"This is my second time being on Zoom, I was very nervous for the technical part of it, but I figured it out, and once I got that I was fine. It is nice being able to actually see your face instead of just over the phone, because sometimes that's just hard to know did you want more…it's like I'm sitting across the table from you." (810-818)
9	"With Zoom…I'm looking at you and I'm seeing who is interviewing me. It's more like we're doing it in person…[we're] able to have that interaction…. It's almost better because I can do it anywhere, anytime." (666-675)

Discussion

Nurses in LTC face communication challenges to due to workflow demands, nurse-patient staffing rations and regulatory burdens (O'Conner-Von & Bennett, 2020; Towsley et al., 2015). Since the outbreak of the COVID pandemic in March 2020, nurses have coped with increased patient mortality and social isolation which have added to nurses' stress (Curtis et al., 2020). Participating in in-depth qualitative research interviews at any time presents LTC nurses with additional personal and professional time-management challenges. During the COVID pandemic, public health guidelines and restrictions on access to healthcare facilities have resulted in research studies being suspended or postponed. Conducting in-depth, in-person qualitative research interviews safely for LTC nurse participants is not currently feasible. However, this novel application of a virtual videoconferencing software application permitted qualitative research to be conducted with LTC nurses safely and securely. This study employed this innovative research method to yield qualitative textual data about nurse-resident EOL care communication that will be analyzed and presented in the future. Though this study's sample size was small, participant response to being interviewed virtually via

videoconferencing was uniformly positive, akin to an in-person interview, and participants indicated they preferred virtual research due its increased convenience. This study gave the researchers an opportunity to learn about effectively employing virtual videoconferencing as a method for conducting future qualitative research. The primary researcher's and participants' observations of the benefits and challenges of employing this data gathering method, summarized below, are consistent with extant literature on employing Zoom videoconferencing software to conduct qualitative research interviews with clinical nurses (Archibald et al., 2019).

Benefits:

1) Immediacy - virtual research via videoconferencing software application allows researchers to gather data about phenomena and experiences immediately from participants, obviating travel and other in-person research burdens while permitting real-time research regardless of researcher or participant location or contact restrictions. This was a significant benefit for the researchers and participants.

2) Convenience – videoconferencing software applications permits data gathering according to participants' schedule and needs, reducing participant burden. This was noted by participants as a significant benefit.

3) Interactive – recent technological advances in videoconferencing software applications means researchers and participants can verbally and visually interact with each other face-to-face in real-time, providing an interactive experience for both parties. Videoconferencing interactivity is an improvement over telephonic interview methods. Participants and the primary researcher noted this benefit.

4) Safety – virtual data gathering allows participants and researchers to interact safely, decreasing exposure to hazards and other factors which might impinge on their respective safety and wellbeing.

5) Security – videoconferencing software applications such as Zoom allow secure data gathering in password-protected interviews designed to enhance security of participant data. Utilizing secure cloud-based storage of recorded video interviews enhances participant data security.

Challenges:

1) Internet instability – virtual videoconferencing interviews requires stable, robust internet capacity for researcher and participant interactivity. Latency in communication was an occasional challenge for the primary researcher and participants, depending on their respective location, requiring occasional repetition of questions and answers by both.

2) Limited presence – The primary researcher's reflexive field notes occasionally questioned whether the interview's virtual nature may have diminished the experience of interpersonal presence compared to being in the same room. However, video recordings show both parties observing pauses for reflection and expressing a full range of emotions throughout the course of the interviews.

Tips for Conducting Virtual Qualitative Research

Conducting qualitative research virtually with nurses in LTC was a novel experience for both participants and the researchers. Conducting a meeting or interview virtually has drawbacks and limitations, whether via Zoom or another videoconferencing

software application. Based on the experience of conducting this qualitative research study virtually, below are suggestions for conducting future virtual qualitative research:

1) One-to-one interaction is preferrable – The virtual dyadic interviews worked in part because the primary researcher and participant could focus on each other exclusively; latency, or lag in interactive communication was also minimized. If this study was conducted with multiple, simultaneous participants, such as in a focus group, interpersonal presence, verbal and non-verbal interactions might have been reduced.

2) Reduce background noise and distraction – Decreasing the primary researcher's visual, acoustic and other background distractions by choosing a private, neutral, quiet space to conduct interviews, and ensuring the researcher's camera, microphone and lighting were optimized helped participants focus on the interview topic.

3) Be prepared to exert more energy and effort to communicate – The primary researcher's reflexive field notes observed that more expressive energy used in interviews often resulted in more participant engagement and expression. Researchers displaying more energy verbal and non-verbal communication energy may result in participant reciprocity with more engagement and focus.

4) Pause the interview and reconnect at a better time if necessary – Unforeseen interruptions or technological difficulties may prevent completion of an interview. During the course of this study, two interviews had to recess and restart at a later time to ensure interactive communication and participation.

5) Maintain a flexible schedule – Ensuring participant convenience and safety in scheduling and conducting their interview required the primary researcher to maintain a malleable calendar to accommodate participants.

6) Know your participants, set expectations – Having participants complete a pre-interview demographic survey of pertinent education and experience helped the researchers understand participants' unique background and make efficient use of interview time. Initial interview questions were provided prior to interviews to encourage participant preparation and set expectations.

Conclusion

An innovative application of a videoconferencing software application permitted the collection of real-time qualitative research data during the COVID-19 pandemic while adhering to public health and institutional research guidelines and contact restrictions. Ten LTC registered nurses, each with more than two years of clinical experience, described their experiences communicating with older adult residents and their families regarding EOL care planning. Participants were individually interviewed virtually using the University of Minnesota's secure Zoom videoconferencing application following an interpretive phenomenological framework. Nurse participants were uniformly positive about the convenience, quality, interactivity and security of this method of data gathering, perceiving no difference between virtual and in-person interviews. This technology offers a safe, secure and effective method to gather qualitative data, even during the COVID pandemic. Virtual, secure videoconferencing's benefits for qualitative research include immediacy, convenience, interactivity, safety and

security, while also presenting challenges from internet instability and limited presence. Suggestions were offered for conducting future virtual nursing qualitative research. Gathering data via virtual videoconferencing could have a positive impact on the safety, convenience, security and immediacy of gathering data for nursing research.

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CHAPTER 4

Long-term Care Registered Nurses' End-of-life Care Communication Experiences with Residents and Families: An Interpretive Phenomenological Study

Overview

Chapter 4 presents the results of a research study describing LTC registered nurses' experience communicating with residents and their families about EOL care preferences and choices to elucidate their experiential knowledge and insights about this phenomenon. The background, theoretical framework methods, data analysis and results are presented, along with a discussion of LTC nurses' EOL care communication process.

Chapter 4 Summary

Registered nurses lead care planning in LTC, yet there are knowledge gaps regarding their communication with residents and families about EOL care preferences. Using an interpretive phenomenological framework, a purposive sample of 10 LTC registered nurses were virtually interviewed to describe their EOL care communication experience. A thematic content analysis employing Parse's theory of Humanbecoming found four concepts: Being Together, Becoming Clear to Become Comfortable, Advocacy to Honor Residents and Unique Impact on Nurses, are all part of their commitment to a continuous, dynamic EOL care communication process. Nurses commit to ongoing whole-person assessment and education, becoming proactive advocates for resident-centered, goal-concordant care. Their knowledge is experientially derived as their nursing education did not adequately prepare them for EOL care communication or complex, multidimensional relationships with residents and families. Further research is needed to evaluate the nature and interaction and relative contribution of the components of EOL care communication in LTC.

Introduction

End-of-life (EOL) care for chronically ill older adult residents diagnosed with multiple co-morbidities who reside in long-term care (LTC) facilities is a complex process that unfolds over time (Amblàs-Novellas et al., 2015). Staff, residents and families in LTC recognize that communication to guide and inform residents' EOL care preferences and choices reduces uncertainty in EOL care decision-making and improves perceptions of quality of EOL care, yet this communication remains challenging due to clinical uncertainty surrounding residents' final stages of life (Amblàs-Novellas et al.; Brazil et al., 2017). Through advance care planning (ACP) is regarded as a standard intervention for determining and documenting LTC residents' EOL care preferences, there are few high-quality guidelines for initiating ACP, evaluating patients' mental or communication capacity to engage in ACP, sustaining conversations, recording care preferences or including family in decision-making processes (Piers et al., 2018).

For the purposes of this study, several terms were defined. Residents were defined as seriously ill older adults residing in LTC while living with at least one advanced-stage disease or multimorbidity frailty. Family was the social group, including surrogates, designated by the resident to make their health care decisions if they became incapacitated. End-of-life referred to the timespan from weeks to years that residents live in a state of declining health. Long-term care referred to temporary or permanent residential healthcare facilities, including skilled nursing, memory care and assisted living. An operational definition of EOL care communication was an iterative, discursive process between nurses, residents and their families to clarify and document the

resident's treatment choices and preferences to guide their EOL care, informed by the resident's values and goals.

Demographic trends show progressive aging of the U.S. population and a significant increase in the number of adults with multiple co-morbidities and advanced chronic disease living in LTC facilities (Amblàs-Novellas et al., 2015; Centers for Disease Control and Prevention, 2016). Under the Center for Medicare & Medicaid Services' 2017 regulations, U.S. LTC facilities are required to provide ACP services to all their residents (Center for Medicare & Medicaid Services, 2017). Engaging in ACP and related communication in LTC to determine EOL care preferences is associated with improved EOL care outcomes for residents (Dixon et al., 2018). Similarly, resident and family satisfaction with the quality and goal-concordance of EOL care are also associated with communication about resident EOL care preferences and choices (Gilissen et al., 2017; Towsley et al., 2015). However, it is estimated that less than 50% of the current 2.1 million U.S. LTC resident residents have completed an advance directive, with little variation between healthy and chronically ill adults (Rao et al., 2014; Yadav et al., 2017).

In LTC settings, registered nurses lead resident care rather than doctors (Hanson & Henderson, 2000). With their unique professional role and relationship with residents, registered nurses are a nexus for EOL care communication and a decision-making facilitator with residents and their families (O'Conner-Von & Bennett, 2020). Effective EOL care planning interventions in LTC are associated with nurses' cumulative experience and willingness to initiate these discussions (Gilissen et al., 2017; Towsley et al., 2015). Even with clinical experience, LTC registered nurses are challenged to

communicating with residents and families about EOL care preferences and documenting their choices due to systemic and individual barriers. Nurses in LTC face multiple barriers to communication and relationship formation with residents and families, including time and workflow constraints, lack of EOL care communication training and fragmented communication patterns with residents, families and other clinical staff (Lund et al., 2015; Towsley et al.). Kim et al. (2015) noted that even though documenting LTC residents' EOL care preferences increased the probability residents would receive goal-concordant EOL care, nurses had difficulty interpreting and explaining POLST care options to them and their families. The unpredictability of a resident's future prognosis and complex contingencies within each comorbidity presents another obstacle to LTC nurses' efforts to educate residents and families about their EOL care options (Barnato, 2017). Barnato also found LTC residents' and their families' lack of familiarity with the impact and consequences of their possible choices challenged their comprehension of EOL care planning. Residents in LTC and their families need timely, relevant information and support to understand the relative risks and benefits of their EOL care options and communicate their preferences and decisions (Towsley et al.). However, LTC residents and their families are reluctant to initiate EOL care discussions, waiting for clinicians to initiate them (Sharp et al., 2013). Dinç & Gastmans (2013) concluded that developing a close, trust-based relationship between nurse and patient was crucial for care planning and management. Ingravallo et al., (2018) emphasized the importance of the LTC nurse-resident relationship in designing EOL care communication interventions, noting that residents' articulation, and nurses' comprehension, of goals, values, concerns,

hopes, future plans and attitudes are all important to support effective EOL care communication.

Jimenez et al.'s (2019) comprehensive synthesis of 80 systematic reviews covering 1,662 studies of ACP revealed major knowledge gaps about EOL care communication initiation, timeliness, optimal content, and impact. Measuring the relative contributions of individual components within complex ACP interventions in LTC is an ongoing challenge (Hickman et al., 2019). The shortcomings of current EOL care communication interventions in meeting their objectives points towards the difficulty of implementing communication necessary to foster comprehension and collaboration between LTC nurses, residents and families. Current ACP interventions are not a complete solution for elucidating LTC residents' EOL care preferences and focusing on advance directive documentation as the output of ACP diminishes the value of a facilitated process that encourages residents and families to reflect on goals of care and EOL care preferences. (Swetz et al., 2014). There is a gap between the identified need for EOL care communication in LTC and nurses' capacity to initiate or sustain it (Gilissen et al., 2017; Wenger et al., 2013). This gap has significant consequences for all stakeholders in LTC, negatively impacting residents' quality of care, resident and family satisfaction with EOL care, and nurses' work satisfaction and resiliency (Brinkman-Stoppelenburg et al., 2014; Houben et al., 2014; Walczak et al., 2016). Advance care planning interventions' efficacy in LTC settings have been reported in the literature (Brinkman-Stoppelenburg et al.; Gilissen et al.; Houben et al.; Klingler et al., 2016; Lund et al., 2015; Walczak et al.). Though registered nurses experience with EOL care in LTC has

been reported, there is a lack of qualitative descriptive knowledge about their experience communicating with residents and families regarding EOL care preferences and choices (Bennett et al., *in press*).

This study contributes to the developing body of nursing knowledge regarding communication for EOL care planning between LTC nurses, residents and their families. Describing experienced LTC nurses' communication strategies and facilitators could inform EOL care nursing education, enhance LTC nurses' capacity to develop trust-based relationships essential to EOL care discussions with residents, and improve the efficacy of current EOL care communication interventions in LTC.

Aim

Describe LTC nurses' experience communicating with residents and their families about EOL care preferences to elucidate their knowledge and insights about this phenomenon. Data collected from individual interviews with a purposive sample of 8-12 registered nurses with a minimum of 2 years of clinical practice in LTC will be thematically analyzed for concepts using an interpretive hermeneutic phenomenology.

Theoretical Framework

Parse's Theory of Humanbecoming (THB) is the theoretical lens for this study's analysis of LTC registered nurses' experience of the EOL care planning communication process with residents and families (Parse, 1998). Rooted in existential-phenomenological thought and universal in its application, THB envisions human perception of phenomena as cocreated within nurse-patient relationships. The meaning nurses and patients derive from their relationships with each other is not bound by a

specific context or group of people However, THB recognizes that meaning from relational experiences is influenced by a person's time, place and situation. Humanbecoming theory is grounded in four principles: (1) all persons are experts in their own lives; (2) life and health, or lack of it are a dynamic process of becoming, not a static state; (3) nursing's goal is to enhance quality of life from the patient's perspective; and (4) nursing practice is a mutual process of exploring values and meaning through lived experience (Parse, 1998). Humanbecoming was chosen as this study's theoretical framework because it incorporates several aspects of EOL care communication in LTC: the dynamic relationship cocreated between nurse and resident as it evolves; a nurse striving to understand a resident's goals and values to advocate for EOL care concordant with the resident's definition of quality of life; and a relational process which that carries significant meaning for both nurse and resident. Nurses and residents in LTC form close relational bonds that are unique in the spectrum of healthcare settings because they interact daily over long periods (O'Conner-Von & Bennett, 2020; Strang et al., 2014). Their relational bonds foster mutual trust that facilitates nurses' comprehension of residents' goals, values and quality of life definition which inform their EOL care choices. Their trust-based relationship helps the nurse and resident navigate the dynamic evolution of EOL care comprehension and preferences as the resident's health declines over time (O'Conner-Von & Bennett). Communication for EOL care planning between nurse, resident and family influences the interpersonal and intrapersonal meanings arising from their experiences (O'Conner-Von & Bennett; Strang et al.).

Method

This study used an interpretive phenomenological framework with a purposive volunteer sample of LTC registered nurses. Interpretive or hermeneutic phenomenology is a systematic, intersubjective study of individuals making meaning from their lived experience (Laverty, 2003). Through individual interviews, registered nurse participants described their developed knowledge and attributed meaning from their experiences communicating with residents and families about EOL care planning. Constructivism grounded the analysis of participants' descriptions of their lived experiences (Bevan, 2014). Each participant's interview was conducted by the researcher, following Van Manen's interpretive phenomenological interviewing guidelines (van Manen, 1990). Van Manen's guidelines employ participants' lived experiences to constitute the phenomenon, elucidating their experientially developed knowledge and meaning attached to this knowledge. Interpretive phenomenology is the appropriate method for gathering data from LTC registered nurses about the dynamic reality of their EOL care communication with residents and families. Studying communication within this relational phenomenon by other qualitative means, such as observation, would not yield insightful data on this phenomenon because participants' intent, motivation and meaning would be difficult to access with other qualitative methods. Intent, motivation and meaning of their developed knowledge are crucial to understanding how and when LTC registered nurses choose to initiate and sustain EOL care communication.

Ensuring Study Quality Assurance & Rigor

This study ensured rigor and quality in its approach, methodology, design, reflexivity, interview protocol and analytical interpretation of data to meet the relevant Consolidated Criteria for Reporting Qualitative Research (COREQ) criteria for qualitative research studies (Tong et al., 2007). Its design and methodology addressed Tong et al.'s criteria for enhancing researcher reflexivity, rigorous study design and a setting conducive to ensuring quality in data collection, saturation and analysis. Lincoln & Guba's (1985) criteria were employed to increase this study's dependability, credibility, confirmability and transferability. Credibility was enhanced through its phenomenological framework; dependability through transparency of its interview methodology; confirmability from its articulated processes to improve data accuracy and explication of the data's meaning and thematic analysis; and transferability from ensuring this study's data and findings have relevance and applicability for LTC nursing knowledge and practice in all contexts and settings.

Feasibility

Nursing research in LTC has demonstrated the feasibility of gathering qualitative evidence from nurses, residents and families about their respective EOL care experiences (Dinç & Gastmans, 2013; Touhy et al., 2005), yet none of the literature has focused on their communication process (Bennett et al., *in press)*. O'Conner-Von & Bennett (2020) conducted a focus group study with 14 registered nurses in LTC who described their EOL care communication strategies and practices to clarify residents' EOL care preferences developed through cumulative clinical experience. These nurses described the exacting

professional and personal toll from the LTC EOL care communication process, emphasizing their advocacy for resident-centered EOL care and deep, close relationships with residents and families while noting the years of clinical experience needed to acquire sufficient communication skills, insight and expertise (O'Conner-Von & Bennett, 2020).

Setting

Registered nurse participants were recruited from an urban, suburban and rural LTC facility in the upper Midwest. These settings were chosen to represent socioeconomic and racial diversity in their resident populations. The rural LTC facility, with a total of 110 beds and approximately 30 miles from a major metropolitan area, has a predominantly Caucasian and socioeconomically diverse resident population. The suburban LTC facility, with a total of 190 beds, has a majority Caucasian and socioeconomically diverse resident population. The urban LTC facility, with a total of 190 beds, has a racially and socioeconomically diverse resident population. In larger LTC facilities such as these, registered nurses simultaneously provide care across multiple units to residents with a spectrum of co-morbidities. The three LTC facilities in this study were chosen to reflect the integration of clinical nursing practice within LTC, with each having skilled nursing, assisted living and memory care units.

Participants

The study's recruitment and enrollment protocols and procedures were approved by the University of Minnesota Institutional Review Board (IRB). A private Minnesota-based LTC organization supported participant recruitment and enrollment for this study.

In response to public health contact restrictions as a result of the COVID-19 pandemic and adhering to current research guidance from the University of Minnesota's IRB and Office of the Vice President for Research restricting in-person research, all nurse participants for this study were recruited and enrolled electronically through email using a recruitment flyer and a letter introducing the researcher and this study (Appendices B & C). Given previous phenomenological interview studies about nurse-patient communication, it was estimated that a sample of 8-12 participants from a diverse LTC nurse population would be required to achieve interview data saturation (Peden-McAlpine et al., 2015). Registered nurses were eligible for this study if they had more than 2 years of clinical experience in LTC, were at least 21 years of age, proficient in English, employed at least 20 hours per week at the LTC facility, consented to voluntarily participate in this study through at least one 90-minute recorded interview with the researcher via the University of Minnesota's secure Zoom (2020) videoconferencing software application, and were willing to discuss their experience communicating with residents and families about EOL care planning. The population of experienced LTC registered nurses was targeted due to the positive association between nurses' clinical experience with EOL care and efficacy of EOL care planning communication (Efstathiou & Walker, 2014; Gilstrap & White, 2015; Reinke et al., 2010).

The study recruitment flyer and letter of introduction were emailed to the Directors of Nursing at an urban, suburban and rural LTC facility operated by the abovementioned organization with the approval and support of its Chief Clinical Officer. The Directors of Nursing circulated the study recruitment flyer to all eligible registered

nurse employees, directing them to contact the researcher directly via email if they were interested in volunteering to participate in the study. Recruitment emphasized the study's potential research benefits: (1) the opportunity to explore and describe their EOL care communication experience; and (2) their insights and knowledge would be disseminated, contributing to the breadth and depth of LTC nursing knowledge and science. Eligible nurses who volunteered to participate were enrolled through email communication following study protocols. As part of its approval process, the IRB determined that participants' formal consent was not necessary but the researcher informed participants prior to their interview about: (1) the study's purpose; (2) the researcher's affiliation with the University of Minnesota School of Nursing; (3) study protocols to assure participant confidentiality and data privacy through de-identification procedures, data safety and secure data storage; (4) participant affirmation of video recording of their interview; and (5) initial interview and demographic survey questions.

Procedures

Data Collection

To ensure participant safety restricting in-perron interaction and adhere to IRB-approved study protocols during the COVID-19 pandemic, each enrolled nurse participant was individually interviewed by the researcher for approximately 90 minutes via a unique, secure weblink to the University of Minnesota's Zoom videoconferencing application (Zoom, 2020). Since the secure videoconferencing application was accessed electronically, each participant chose the date and time most convenient for them to be interviewed, either at work in a private meeting room or at home. The security and

integrity of all data were ensured by restricting access to recordings and transcripts to the research team per study protocol, and by following the University of Minnesota School of Nursing's institutional guidelines for data privacy protection in research studies. Participation in this study was voluntary and each participant's decision about whether or not they chose to participate was solely their own choice. Participants were not required to answer any questions and could choose to end their participation at any time during the interview without explanation or penalty and data collection would cease upon their withdrawal. None of the participants withdrew from the study nor refused to answer any interview question. The researcher created a checklist for adherence to the interview protocols and ensure each participant received the same consent and enrollment procedures (Rubin, & Rubin, 2012; van Manen, 1990). Each enrolled participant received an email from the researcher containing the study recruitment flyer, a personalized letter summarizing the study's procedures, purpose and protocols, a calendar invitation with the date, time and secure weblink for their interview, and a copy of the demographic survey and initial interview questions (Appendices B, C, D & E). Before their interview, each participant received an electronic message confirming their receipt of the abovementioned email and its attachments.

Each interview began with the researcher reviewing the study's purpose, procedures, participant data safety and confidentiality protocols, and verbal consent for participation in and recording of the interview. The researcher began each interview with several initial questions to focus the interview on the phenomena of interest: EOL care communication with residents. Interview questions, summarized in Appendix E, were

designed to elucidate participants' developed knowledge and insights about EOL care communication. Nurse participants also answered demographic survey questions. A modest financial incentive in the form of a $50 gift card was offered to each participant to compensate them for their time at the end of their interview. This incentive was paid for out of the primary researcher's personal funds. Per study protocol, each participant subsequently had an opportunity to review a transcription of their interview to offer feedback, provide clarification on language and meaning, or stimulate additional contributions to their interview data from their experience. Participants were enrolled and interviewed until the transcribed textual data and interviewer field notes indicated sufficient data had been generated to achieve saturation. Saturation was reached when the language content of interviews did not reveal any novel data (Rubin & Rubin, 2012).

Recording

Each interview was simultaneously video- and audio-recorded to assure data backup and enable fidelity auditing procedures. The video recordings were professionally transcribed verbatim by a University of Minnesota School of Nursing private contractor with substantial experience in transcribing qualitative research interview data. The audio recordings were used both by the contractor to clarify researcher questions and participant responses and by the researcher to assure transcription fidelity. The researcher also wrote reflexive journal notes after each interview as part of the interpretive phenomenological research process and used these notes as part of his data analysis (Bevan, 2014).

Data Analysis

Employing an interpretive hermeneutic approach, textual transcriptions and video recordings of each interview were analyzed to identify participants' developed knowledge and attributed meaning from their experiences of what, how, when, where and with whom they communicate about residents' EOL care planning. In coding participants' language from the data, close attention was given to participants' descriptions of their consequential actions, antecedent motivations, attitudes, values, beliefs, explicit and implicit knowledge. ATLAS.ti qualitative data analysis software, version 9.0.3, was used for coding and categorization of textual transcribed data (Atlas.ti, 2020). The analytical findings were organized and categorized using interpretive, or hermeneutic principles with verbatim quotes from the data that illustrate and faithfully represent the participant's language (van Manen, 1990). To identify core meanings of the participants' experience and capture the phenomenon, the data analysis focused on essential themes that were critical and unique to the phenomenon of EOL care planning communication, as opposed to incidental themes. Language from the primary researcher's reflexive journal notes was also analyzed to incorporate the co-creation of meaning that occurs between interviewer and participant during interpretive phenomenological interviews (van Manen, 1990). Bevan's narrative analysis research process (Figure 1) was used to guide the examination of participants' descriptions within a naturalistic, interpretive constructivism paradigm (Bevan, 2014).

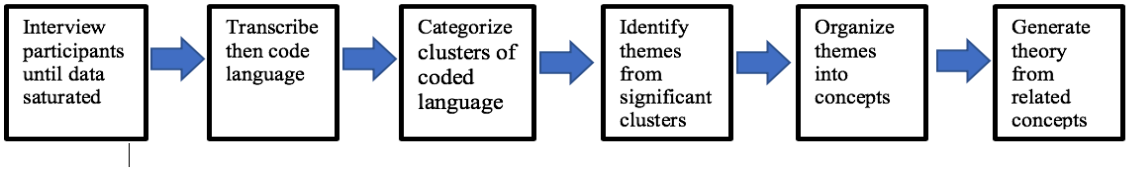

Figure 1 - Bevan's Interpretive Phenomenological Data Analysis Framework

Participants' language was noted and coded for descriptive phrases, words, metaphors, similes, images, actions, thoughts and feelings. Analysis of the coded language was formed into clusters of similar categories of codes. The researcher created memos in the data analysis process to identify and organize significant code category clusters into phenomenological themes, which in turn yielded concepts discussed below. Interrelated concepts in this study could be used to support theory generation in future research that may provide additional insight into the phenomena (Bevan, 2014).

Results

Ten registered nurses who met the eligibility requirements in the abovementioned urban, rural and suburban LTC facilities were enrolled as volunteer participants, each acknowledging and affirming their verbal consent to the study and its procedures. Participant characteristics are summarized in Table 1. With an average of 12.2 years and a range of 6 - 27 years of LTC clinical nursing, the participants all had considerable experience with EOL care communication.

Table 1 - Characteristics of Nurse participants

Registered Nurses	Sample (n = 10)
Sex: M : F ratio	0 : 10
Avg. Age	48.2
Avg. total LTC nursing experience (range)	12.5 Years (6 – 27)
Facility Setting	60% Urban 20% Suburban 20% Rural
Education	30% ASN (Associate) 70% BSN (Bachelor)
Source of EOL care communication education	90% workplace experience

Each participant expressed support for this study and generously shared their experiences, insights, thoughts and feelings about EOL care communication with residents and families. Common codes, categories and themes were observed in all participants' language and reflected in the data analysis regarding their relevant experiences, though there was some variability between individual participant's emphasis on specific aspects of the EOL care communication process. This variability was mostly due to the range of individual participant's respective experiences and perceptions of the phenomenon. Table 2 summarizes the frequency of data coding for each of the 10 participants and the four concepts derived from the data analysis. Table 3 encapsulates the data analysis results along with pertinent verbatim quotes from participants' interviews to ground thematic development.

Table 2 - Data Coding Frequency Variation by Participant & Concept

RN Participant	Being Together	Becoming Clear to Become Comfortable	Advocacy to Honor Residents	Unique Impact on Nurses	Total Codes per Participant
1	8	25	39	10	82
2	13	26	55	2	96
3	25	30	32	6	93
4	18	38	46	2	104
5	27	31	49	8	115
6	60	35	41	5	141
7	57	24	38	7	126
8	21	33	41	8	103
9	26	42	31	2	101
10	33	44	35	10	122
Total Codes per Concept	288	328	407	60	1083

Table 3 - Concepts, Themes. Categories & Quotes

Concepts	Themes	Categories	Quotes
1. Being Together	1A. Primacy of trusting relationships precedes communication, comprehension & collaboration	1Ai. Relationship & Trust-building	*"Develop a relationship, develop a trust relationship and really get to know them, not as a number, or a body, or somebody else I have to pass meds to." (1:536-537)* *"We're taking care of this resident, because it's like taking care of your family member now. I mean, this person is here and they depend on you at this moment." (5:252-254)* *"[Resident] wasn't talking that much but she told [another nurse] that she was waiting for [me]....I walked in and I touched her hand and she opened her eyes and she saw it was me, and she sat straight up in bed and she said oh, I just wanted to let you know I believe in God now and I'm ready—boom—back down, and then she died later that night. I'm like I have no idea why she needed to tell me that, but she had struggled, and struggled, and struggled with dying until I think that was her acceptance, that she was going to go. I don't know if it had to do with her faith or what, but just finally...yeah, that was an experience." (6:549-557)* *"You don't just go and ask, 'What do you want to do when this time comes?' It's way broader. You talk about their past and where they've come from, different traditions and customs and things that they like, things that are important to them." (10:164-168)*
	1B. Constant communication with residents and families builds foundation for comprehension & collaboration	1Bi. Asking, learning & listening	*"You get to know the people...like what's [their] culture and what they like to do, and then what their faith is. Faith is a big part of a lot of people's journey no matter what faith they are. It makes a big difference when they make decisions." (6:508-511)* *"When I say nursing and listening, it's also watching body language, so you're kind of listening like how they move, how they act, what they don't say, and what they do say." (6:364-365)* *"You've seen what has worked for this person, and you actually see them with their family members, because you're there all the time with them, seeing what they would want to happen to them. That's where the conversation starts.' (9:69-72)* *"In order for you to paint this whole picture of this person, you need to go well beyond that nursing assessment. It's just the tip of the iceberg." (10:226-227)*

Table 3 - Concepts, Themes. Categories & Quotes continued

Concepts	Themes	Categories	Quotes
2. Helping each other with becoming, becoming clear to become comfortable	2A. Consistent communication to ensure residents & families become clear about, and comfortable with EOL care	2Aii. Ensuring comprehension	▪ *"Try to paint as clear a picture as you can….Even if it was a family member who is here close, they're not able to come in and see their loved one on a daily basis, so I think painting a daily picture of how [the resident's] time has been recently [for the family], 'This is how I saw them maybe two months ago and now this is what I'm seeing today.'" (4:367-370)* ▪ *"I think putting it in layman's terms for them is…helpful, just being honest." (4:444-445)* ▪ *"[Comprehension is] very individualized, individually based….You obviously ask particular questions, but every situation is very different." (10:250-251)* ▪ *"You explain to the person without scaring them what is happening. A lot of people, they don't have knowledge of what's going on. If you give them that knowledge, explain to them what is happening beyond their diagnosis, I think they understand it." (10:293-295)*
	2B. Becoming is mutual, experienced interpersonally & intrapersonally by nurses, residents & families	2Bi. RN facilitators	▪ *"The same way doesn't work for all of them, that's for sure. Everybody is different…no cookie cutter way. Some you need to be a little more direct with. Some you need to be a little more compassionate with. It depends on the person. You get a feeling for, OK, this isn't going to work for them, so I need to try something else." (4:556-559)* ▪ *"Knowing that different cultures do this process differently." (6:162)* ▪ *"When you listen to them…I mean with my years of experience, I would know that when I try to be fast that I don't get anything done because I'm not going to get the information I need, so that will make me to know to slow down, and this is how you need to examine if you want to hear this information. You have to calm down." (9:393-396)* ▪ *"You can't do it by yourself. You need to rely on your team…you need to do it together. If you think that you are good enough or smart enough to do it by yourself, you're probably going to fail…you need to humble yourself and understand that you need others around you." (10:748-751)*
3. Compassionate care ensures residents are honored	3A. Advocacy drives EOL care communication persistence, informs nurses' purpose & role	3Ai. Advocacy	▪ *"Here you are, the resident wants this and the family wants this—oh, you are just caught in between here. But my priority is for the resident. If that's what they have decided, and he or she has said…this is what I want, then it's for me to support [the resident]." (5:278-281)* ▪ *"What I learned is to respect the resident and the resident's autonomy, whatever they decide on such things….be there for them, you know support them by all means, and make them as comfortable as possible." (5:696-700)* ▪ *"This is not about us; it's about this patient and if you really care for this patient, you're willing to work together to see how well she's being cared for." (9:210-202)* ▪ *"You have this conversation, regardless of if the family is not ready, because as a nurse, as a professional, you have to advocate for your patient." (10:612-614)*

Table 3 - Concepts, Themes. Categories & Quotes continued

Concepts	Themes	Categories	Quotes
3. Compassionate care ensures residents are honored	3A. Advocacy drives EOL care communication persistence, informs nurses' purpose & role	3Aii. Family obstacles	▪ *"Death isn't the enemy, but for the living, it seems like it is." (1:580-581)* ▪ *"Difficult families aren't the ones that have…a goal and a plan. Difficult families, to me, are the ones that I can never reach or get hold of." (2:295-298)* ▪ *"We have so many cultures, people from different backgrounds. Some people don't talk about death…. They don't want to talk about that. If it comes, it comes it's natural, but we're not going to plan for it." (5:147-152)* ▪ *"It's a hard conversation to have, especially when it comes to family. They don't want to hear it, and if family are the ones that need to make that decision, they don't want to feel the guilt….The family doesn't want to feel that they're making that decision for that person." (9:130-137)*
		3Aiii. Resident obstacles	▪ *"Most [residents] are fearful coming in because they are unable to maintain their same routines….It's like a letting go of what was." (3: 131-136)* ▪ *"When he first got here, he didn't want [to discuss EOL care planning]. He wanted a cure and he wanted to go home" (6:352-353)* ▪ *"Some people just are so set in their ways; they're not willing to [discuss EOL care]. And some people just want other people to make the decision for them. And some people are so afraid to die that you can't get past that." (7:345-348)* ▪ *"[Some residents] don't want to talk about death; they don't want to talk about hospice. It's just this big stigma and it's a big, big scare. Maybe there's denial in there, too. They think if I don't talk about it, then it's not going to happen." (10:133-135)*
		3Aiv. RN obstacles	▪ *"I don't know that some of the nursing staff, or some of even the social workers, or whoever we're having address [EOL care communication], if they really can answer [their own EOL care] questions themselves or think about who would help them answer those questions." (2:847-850)* ▪ *"When I was in school, they don't teach you any of these experiences. They teach you the basics. They teach you: these are your stages, these are what the person's going to experience, like their body effects and stuff like that. But they don't teach you how to have these conversations with residents, how to communicate, and how to start those conversations." (9:439-443)* ▪ *"You have so many tasks to do. [You] are more task-oriented, because [you] have this, this, this, and this. So, a lot of time you don't have the time to sit and talk, and talk, and talk to the residents." (11:620-622)* ▪ *"End-of-life stuff is not addressed enough in nursing school. We learn so much about different diseases, which is absolutely needed, and how to do an assessment, but this end-of-life piece, it's a huge piece. We may not all get diabetes or heart failure, but we're all going to die from one thing or another." (12:765-768)*

Table 3 - Concepts, Themes. Categories & Quotes continued

Concepts	Themes	Categories	Quotes
3. Compassionate care ensures residents are honored	3B. COVID has positive and negative effects on EOL care communication for all stakeholders	3Bi. COVID effects	▪ *"I call it the enemy, but yeah, it's like a sniper. It's like a war. It's very much like a war….In combatting a virus that can be so deadly, and especially to the vulnerable. And here we are, our calling has been to care for the vulnerable, and now there's something that's even making them more vulnerable, and it's like, are you kidding me? How can it get any worse? And then the hard work of long-term care is really, really hard." (1:454-463)* ▪ *"[The staff] are steadfast. They're going to do their job…nobody is running away from it. Nobody is saying, 'I quit.' Nope. They're just staying in it. They might have said, 'Maybe I'll resign,' but they're in it. (1:497-499)* ▪ *"For residents and their families, what used to delay the communication, the decision-making, was, 'Well, we can just go to the hospital,' and the hospital would be a place that would delay any decision, because the hospital would sort of fix them, so to speak….Now, under COVID, a hospital's not a place to fix things; it's actually a place where people can get sick and die." (2:198-206)* ▪ *"We were unable to give what I would consider appropriate care at the level of humanity. There was care, but it wasn't – there was no hand-holding and sitting because there just wasn't the staff for it, and the loved one wasn't present because it was a COVID unit. And it's heartbreaking. It is absolutely heartbreaking and it kills me." (3:235-238)* ▪ *"We had to ask the questions more blunt, because [with] COVID we just didn't know how rapid everything was going to be." (6:658-659)*
4. Unique personal and professional impact on LTC nurses	4A. Nurses are changed by the close relationships with LTC residents and families EOL care communication experience	4Ai. Effects on RN	▪ *"[I had given the resident] Roxanol [morphine sulphate] and…oxygen, but I wasn't sure that we were doing enough to keep [him] comfortable enough with the air hunger, and I think that was hard for me to see, as well. So,[I wasn't expecting that, I think, was the hard part. [nurse becomes emotional, whispers] It hurts." (2:721-724)* ▪ *"We're taking care of this resident, because it's like taking care of your family member now. I mean, this person is here and they depend on you at this moment." (5:252-254)* ▪ *"It's so hard, and even though it can be a beautiful thing, you still have to grieve. That whole process, grieving doesn't end; grieving takes a long time after the death." (7:155-157)* ▪ *"Give them the life they want; give them the death they want. It's like raising a child. That's where you get your joy is in watching them achieve their own goals." (7:705-706)* ▪ *"As a nurse, I feel like I have feelings for these residents, and I want the best for them, I don't want them to suffer in pain. I don't want them to be put through all these procedures that just are keeping them alive so that their family member can see them longer, when they could be resting, lying in bed peacefully, and be comfortable. It's hard to see, when you see these residents suffering, knowing that there could have been a different option or a different avenue we could have taken." (8:625-630)*

Concept: Being Together

The nurse, resident and their family live in a state of being together as they work within their relationship which drives communication. Nurses in LTC employ attunement, awareness and presence to establish deep relationships and facilitate EOL care communication. The Being Together concept is comprised of two themes: (a) the primacy of establishing trust-based, close relationships, which precedes significant communication about EOL care preferences and goals; and (b) staying in constant communication helps nurses build comprehension and collaboration with residents and families. *"Develop a relationship, develop a trust relationship and really get to know them, not as a number, or a body, or somebody else I have to pass meds to." (1:536-537).* Nurses strive to comprehend the resident as a whole person as part of their relationship formation: *"In order for you to paint this whole picture of this person, you need to go well beyond that nursing assessment. [The assessment is] just the tip of the iceberg." (10:226-227)*

Concept: Becoming Clear to Become Comfortable

Once a trust-based relationship is established, nurses communicate with residents and families to clarify mutual understanding about residents' EOL care options and goals so each stakeholder becomes more comfortable with the resident's current preferences and their dynamic health condition. Becoming clear is a continuous process for nurses, not a discrete state.

> *"Try to paint as clear a picture as you can.…Even if it was a family member who is here close, they're not able to come in and see their loved one on a daily basis, so I think painting a daily picture of how [the resident's] time has been recently [for the*

family], 'This is how I saw them maybe two months ago and now this is what I'm seeing today.'" (4:367-370).

The concept of Becoming Clear to Become Comfortable has two themes. First, nurses consistently communicate to ensure resident and family prognostic comprehension:

> *"You explain to the person without scaring them what is happening. A lot of people, they don't have knowledge of what's going on. If you give them that knowledge, explain to them what is happening beyond their diagnosis, I think they understand it." (10:293-295).*

Nurses also use attunement, presence and awareness to ensure they comprehend the resident: "*Using my eyes…with the resident every day, Monday through Friday, for eight hours a day….You use your eyes, ears, and heart, too." (5:244-248).* Second, clarifying and comprehending is a mutual, interpersonal process.

> *"You can't do it by yourself. You need to rely on your team…you need to do it together. If you think that you are good enough or smart enough to do it by yourself, you're probably going to fail…you need to humble yourself and understand that you need others around you." (10:748-751).*

Nurses find through experience that they have to continually adapt to foster residents' and families' becoming:

> *"The same way doesn't work for all of them, that's for sure. Everybody is different…no cookie cutter way. Some you need to be a little more direct with. Some you need to be a little more compassionate with. It depends on the person. You get a feeling for, OK, this isn't going to work for them, so I need to try something else." (4:556-559).*

Concept: Advocacy to Honor Residents

Nurses persist with EOL communication because they recognize that residents' goals and preferences are dynamic and evolve as their health declines. The first theme in the concept of Advocacy to Honor Residents is nurses' commitment to EOL care communication to advocate for goal-concordant EOL care that decreases suffering and

increases comfort. *"Respect the resident and the resident's autonomy, whatever they decide on such things….be there for them, you know support them by all means, and make them as comfortable as possible." (5:696-700).* Knowing the resident's values and evolving definition of an acceptable quality of life guides LTC nurses' advocacy and interpretation of what constitutes compassionate care for the resident as they progress along the EOL care continuum: *"You have this conversation, regardless of if the family is not ready, because as a nurse, as a professional, you have to advocate for your patient." (10:612-614)*. This concept's second theme encompasses these nurses' observations about the COVID-19 pandemic's positive and negative effects on EOL care communication. Mortality salience increased temporarily for residents and families as emergent hospitalization risks temporarily accelerated their willingness to engage in EOL care communication.

> *"For residents and their families, what used to delay the communication, the decision-making, was, 'Well, we can just go to the hospital,' and the hospital would be a place that would delay any decision, because the hospital would sort of fix them, so to speak….Now, under COVID, a hospital's not a place to fix things; it's actually a place where people can get sick and die." (2:198-206)*.

The COVID-19 pandemic posed significant impediments to EOL care communication and collaboration: residents' depression, anxiety and fear increased due to social and physical isolation; families' stress increased due to lack of direct observation of and involvement with the resident; the layers of personal protective equipment (i.e. – masks, gowns, gloves, face shields) hampered communication and relationship formation with residents; and reduced staffing in LTC facilities due to illness, COVID protocols and lack of onsite support staff increased nurses' workload and stress:

> *"I call [COVID-19] the enemy…it's like a sniper. It's like a war. It's very much like a war. Very much like a war…combatting a virus that can be so deadly, and especially to the vulnerable. And here we are, our calling has been to care for the vulnerable, and now there's something that's even making them more vulnerable, and it's like, are you kidding me? How can it get any worse? And then the hard work of long-term care is really, really hard." (1:454-463)*.

However, LTC nurses remained vigilant and steadfast in the face of these additional challenges and obstacles, driven by their role and purpose as advocates for residents' goal-concordant EOL care. *"[The staff] are steadfast. They're going to do their job…nobody is running away from it. Nobody is saying, 'I quit.' Nope. They're just staying in it." (1:497-499)*

Concept: Unique Impact on Nurses

End-of-Life care communication in LTC has unique positive and negative impacts on nurses personally and professionally over time. These impacts occur within specific resident relationships:

> "*I had given [the resident] Roxanol [morphine sulphate] and…oxygen, but I wasn't sure that we were doing enough to keep [him] comfortable enough with the air hunger, and I think that was hard for me to see, as well. So I wasn't expecting that, I think, was the hard part. [nurse becomes emotional, whispers] It hurts." (2:721-724)*

The impacts also accumulate across all their EOL care communication experiences and throughout their practice in general:

> *"As a nurse, I feel like I have feelings for these residents, and I want the best for them, I don't want them to suffer in pain. I don't want them to be put through all these procedures that just are keeping them alive so that their family member can see them longer, when they could be resting, lying in bed peacefully, and be comfortable. It's hard to see, when you see these residents suffering, knowing that there could have been a different option or a different avenue we could have taken." (8:625-630)*.

Nurses in LTC are changed by their close relationships with residents and families and by communication process to ensure goal-concordant, resident-centered EOL care: *"It's so hard, and even though it can be a beautiful thing, you still have to grieve. That whole process, grieving doesn't end; grieving takes a long time after the death." (7:155-157)*. Nurses express that through the EOL care communication process with the resident their relationship with and feelings for the resident become similar to caring for one of their own family members: *"We're taking care of this resident, because it's like taking care of your family member now." (5:252-254).* Cumulative experience communicating with residents and their families also changes nurses' beliefs about their role and purpose in LTC: *"Give them the life they want; give them the death they want. It's like raising a child. That's where you get your joy is in watching them achieve their own goals." (7:705-706).*

Nurse participants described EOL care communication in LTC as a complex, multilevel process that engages all four concepts: Being Together, Becoming Clear to Become Comfortable, Advocacy to Honor Residents and Unique Impact on Nurses, with all of them being part of their commitment to continuous communication. For nurses in LTC, their role as advocates and facilitators ensuring residents receive compassionate, goal-concordant care is the impetus for their initiation of EOL care communication. Their close, deep relationships with residents and families form the trust necessary for continuous communication and support meaningful assessments, leading to mutual comprehension and collaboration. Comprehension guides nurses' advocacy for resident-centered care and collaboration with all stakeholders. Nurses employ all of the process'

components interchangeably and simultaneously as they work to understand the dynamic reality of the resident's health prognosis and evolving preferences and choices. Thus, the four concepts are not divisible into discrete components because they interrelate with each other.

Nurses make several commitments in the continuous EOL care communication process: (1) an ongoing, close relationship with residents and families that carries interpersonal and intrapersonal meaning for all; (2) employing assessment skills, awareness and presence to support the resident and family becoming informed and comfortable with the resident's preferences; (3) providing compassionate, resident-centered care throughout the dynamic, evolving reality of the resident's EOL care; and (4) remaining steadfast and vigilant caregivers, even as the process affects them during and after the resident's life in LTC. Though conditional and not perfected, a visualization of nurses' EOL care communication process illustrates its interactive nature within all four concepts: (Figure 2)

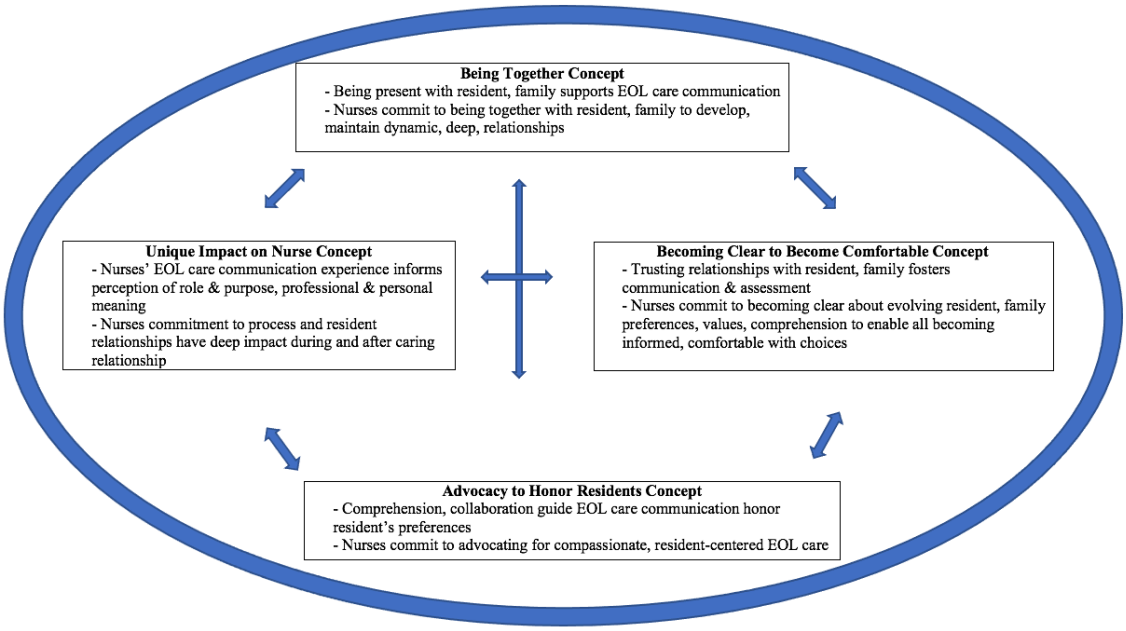

Figure 2 - EOL Care Communication Process in Long-Term Care

Table 4 presents an exemplar of the LTC EOL care communication process learned through experience:

Table 4 – End-Of-Life Care Communication Process Exemplar

"You don't just go and ask, 'what do you want to do when this time comes?' It's way broader. You talk about your past and where you've come from, different traditions and customs and things that you like, things that are important to you. I think sometimes even without asking this question, what do you want when this time comes, if you ask those questions and you know answers to those questions, you're able to paint this picture. These are the things that the person likes, this is what they value, and these are the things that are important to them. You're able to understand better why, where they're coming from….It takes time, first of all. It doesn't happen fast and it's a very genuine interest in the person. It can't be fake, because it can be very easily felt if it's fake. You should be very curious and interested in this particular individual, and it takes time and takes a lot of conversations to know/ one-on-one conversation. Truly be interested in what this person's likes are, have been in the past, some of their family, where they come from. And, also in return, you maybe even share some of the information about your life, about your past with them. It's not just you sitting there and getting all this information out of them; you have to give something in return, so the other person knows some of those facts about you, maybe something you don't share necessarily with other people, with your coworkers or with other residents. It doesn't have to be some secrets, but it's stuff from the heart and something that's important to you, something that defines you as a person, something that you value, something that you're interested in, understand. Obviously, you have to care. I think that's a very important thing and you have to be very genuine about it, very honest about it….We all have a purpose. We don't come to this world just to go through the motions, grow up, go to work, get old. We have something that we're passionate about; we have something that we like that has set us apart from another individual next to us. There's always something and it's just a matter of asking those questions…. Sometimes if you ask the person, 'what are some of your values?' Sometimes it's hard for a person to answer. You also understand that sometimes you deal with a person, some of them have cognitive changes, cognitive impairments, and if I ask the person who has dementia, 'what are some of your values?' they may not be able to answer the question. But if you start talking to them about, 'where did you come from? Where did you grow up? What are some of the things that your mother did for you? What did you do for a living?' That's reading between the lines and you're able to realize some of the things that are meaningful to this person, even without asking, 'what are some of the things that are meaningful for you?' Sometimes even if you ask me that question, I will have to sit and think a little about it, because it's such a broad question. Oh, wait a second, there's a few things that are meaningful. If you sit down and start having this conversation, one-by-one it's kind of like an onion. You just peel the layers and then eventually you get to the core that is truly important…. just to have this very holistic understanding of who this person is. Sometimes maybe some of our nursing assessments, they ask a lot of questions about their physical health, but I think it's very limited. In order for you to paint this whole picture of this person, you need to go well beyond that nursing assessment. It's just the tip of the iceberg. You get this very vague kind of picture of who this person is, and then as you continue to work with them, that's where the interdisciplinary team comes into play, when you work with other departments. You work with social services to understand more of their life prior to coming to the community. Understand if they have spouses, children, anything else, what their occupation was, what kind of living arrangements they had prior to that. All of this shapes who the person is who you're dealing with right now, and sometimes some of the issues, some of the concerns that they have, some of the challenges that you experience with this particular resident, that's the reason why. We are the product of our environment, everything that we've experienced in our life before….[You] also work with community life…you work with therapy….Our nursing department by itself cannot paint this big picture, so they need input from other departments. [You] need to collaborate with other people, in order to be able to paint this picture. That's why you need to ask questions. You need to pay attention when you go to interdisciplinary meetings or you read assessments and read other people's notes. Then you understand who this person is." (10: 164-243).

Discussion

Nurses describe EOL care communication as a continuous, dynamic process employing attunement and presence to understand the resident's goals and needs from a whole-person perspective, which guides their advocacy for resident-centered EOL care. The EOL care communication concepts and themes identified from this study's data incorporate the four principles of Parse's Theory of Humanbecoming (THB). The four concepts identified in the results above: Being Together, Becoming Clear to Become Comfortable, Advocacy to Honor Residents, and Unique Impact on Nurses all incorporate Humanbecoming Theory's four principles. First, LTC residents are experts in their own lives, which includes their EOL care preferences, and nurses learn residents' insights and perspective about their care through clarification and reflection. Second, a resident's life and unfolding of their EOL care is a dynamic process of becoming for resident, family and nurse as the resident's physical, mental, emotional and spiritual conditions evolve across the EOL care trajectory. Third, the nurse's primary goal is to enhance quality of life according to resident's values, and the nurses is informed about the resident's dynamic definition of quality through continuous communication. Fourth, nursing in LTC settings is a mutual process of exploring and interpreting values and meaning through their lived experiences within the relational phenomena. Table 5 summarizes the application of THB to the conceptual data analysis.

Table 5 – Application of Humanbecoming Theory to Study Findings

Humanbecoming Principle	Study Findings	Concepts Incorporated	Illustrative Quotes
1) All persons are experts in their own lives	Residents experts in their EOL care, RN learns through clarification, reflection	Advocacy to Honor Residents, Being Together	*"They will actually tell you how it started and they'll tell you they've lived with it all their life, so they're the right nurse for themselves, because they've lived it before they came here, …and they will tell you what has worked in the past." (9:271-273)*
2) Life and health, or lack, of are a dynamic process of becoming	Life & EOL are a dynamic process of becoming as conditions evolve	Becoming Clear to Become Comfortable, Unique Impact on Nurses	*"Comprehension comes in phases for families and residents, which is where the frequent revisiting of those topics might come in really handy." (3:343-344).* *"This communication is ongoing; it never ends. You can think this is it, but…it just goes on and on." (5:192-194)*
3) Nursing's goal is to enhance quality of life from the patient's perspective	RN's goal: enhance quality of life according to resident's values	Advocacy to Honor Residents, Becoming Clear to Become Comfortable	*"Respect the resident and the resident's autonomy, whatever they decide….be there for them, support them by all means, and make them as comfortable as possible." (5:696-700)* *"They have a different culture than I do....I've got to try to understand it and try to not judge it, so that we can make the patients, make it about them and not about us." (7:682-686)*
4) Nursing a mutual process of exploring values and meaning through lived experience	LTC EOL care a mutual process of nurse, resident exploring values & meaning through lived experience	Being Together, Unique Impact on Nurses	*"It's like you are looking at your own mortality every day….Your expanse in your beliefs changes." (1:239-240)* *"The textbook is different from real life. It will guide you to steps, but then you're dealing with a human being…it's basically you, and your co-workers, and the resident themselves, and family." (9:530-533)*

With experience, nurses learn that being together in a trust-based relationship is the first step in EOL care communication. Forming deep, trust-based relationships develops and deepens EOL care communication, promotes comprehension, and facilitates

collaboration with residents and families (Cagle et al. 2017; Funk et al., 2018). Nurses describe EOL care communication as a continuous relational process that supports the resident's expression of their coping strategies for living with their disease(s). For residents with dementia or other cognitive and verbal impairments, family is key to discernment regarding the resident's EOL care goals and values (Kastbom et al., 2020). Establishing and maintaining close, trust-based relational bonds with family members supports both their ongoing comprehension of the residents evolving condition and collaborative and decision-making. For LTC nurses, the purpose of EOL care communication is to know the resident well enough to honor their choices and preferences, which includes comprehension of a residents' culture. Communication for EOL care planning functions to clarify a resident's evolving definition of quality of life, risks and benefits of care options, and concordance between their expressed values and current EOL care choices. Nurses become proficient in employing presence and attunement in their ongoing observations and assessments to adjust and calibrate their communication strategies and tactics.

The EOL care communication process stimulates mutual discernment, exploration of values and meaning that is both shared and relational as well as unique and individual. Fan et al. (2019) found that EOL care communication prompted LTC residents to reflect on the meaning of their EOL care, then articulate their quality-of-life definition with their families and nurses. Nurses discern their own values and meaning from shared relational experiences, and their perspective about professional role and purpose evolves with cumulative EOL care communication experience. Nurses personally value their

relationships with current and decedent residents, carrying both grief and wisdom from their experience. Kaasalainen et al. (2007) found that cumulative loss from resident deaths affects LTC nurses' resiliency. Nurses in LTC need opportunities to express their grief and loss from EOL care communication relationships and experiences. They also experience moral and ethical distress, prompting them to become proactive advocates when residents received EOL care and their goals diverge.

Finally, nine of the 10 participants perceived their nursing education did not adequately prepare them for the reality of EOL care communication with residents and families in LTC. Participants observed their EOL care nursing education focused on technical and instrumental rather than relational aspects of EOL care. One participant summarized LTC nurses' need for continuing education around EOL care communication: *"End-of-life stuff is not addressed enough in nursing school. We learn so much about different diseases, which is absolutely needed, and how to do an assessment, but this end-of-life is a huge piece. We may not all get diabetes or heart failure, but we're all going to die from one thing or another." (12:765-768).*

Limitations

This study was conducted with a small sample of volunteer registered nurse participants, all of whom work for one regional LTC organization and agreed to participate based on their EOL care communication experiences with residents and their families. This study's findings should be considered in light of the limited size and geographic scope of the sample.

Conclusion

Ten LTC registered nurses with more than two years' of LTC clinical experience were individually interviewed regarding their EOL care communication experiences with residents and families employing an interpretive phenomenological framework. A thematic content analysis of the resultant textual data employing Parse's Theory of Humanbecoming found that four concepts: Being Together, Becoming Clear to Become Comfortable, Advocacy to Honor Residents and Unique Impact on Nurses, are all part of LTC registered nurses' commitment to a continuous, dynamic EOL care communication process. Nurses commit to ongoing whole-person assessment and education and becoming proactive advocates for resident-centered, goal-concordant care. Continuous commitment to EOL care communication is proposed as a looping progression, beginning with nurses' role and purpose which grounds their EOL care communication and is the basis for their initiation of relationship building with residents and their families. Nurses form close relationships with residents and families to build trust, which fosters mutual comprehension and collaboration. Comprehension and collaboration inform nurses' resident advocacy and knowledge for appropriate compassionate care. For nurses, the EOL care communication process and their deep, longitudinal relationships with residents have unique impacts both professionally and personally. Their knowledge is experientially derived and they perceive their nursing education did not adequately prepare them with EOL care communication skills or working with complex, multidimensional relationships fundamental to guiding the process with residents and families. Further research is needed to evaluate the nature and interaction and relative

contribution of the components of EOL care communication in LTC which could support theory generation and concept analysis.

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CHAPTER 5

Synthesis

This chapter summarizes the findings from the three manuscripts that comprise this dissertation and describes these findings' overall contribution to the body nursing knowledge and their implications for nursing education, research, practice and LTC organizational policy.

Results from Manuscript 1 (Chapter 2)

A gap exists in nursing research literature regarding the unique perspective and knowledge of experienced LTC registered nurses communicating with residents and their families about EOL care preferences, indicating a need in the literature for knowledge about this phenomenon. A critical review of the literature found that nurses in LTC learn through experience to lead EOL care communication and advocate for residents' EOL care preferences and ensure their goals of care are honored. Ongoing EOL care communication results in professional and personal benefits and burdens for LTC nurses. The quality of EOL care communication is affected by the organizational resources, support and education they receive. The construct of time was identified, with LTC nurses perceiving time is more or less available depending on the prominence of communication facilitators or barriers, respectively. Applying symbolic interactionism to this review's findings, the meanings that LTC nurses, residents and families derive from communication about EOL care evolves over time. Future research could apply qualitative research methods to describe EOL care communication factors that aid LTC registered nurses in building rapport with residents and families. Identifying the

communication facilitators these nurses employ to understand and articulate resident's preferences, goals and values could inform clinical practice guidelines, nursing education and enhance LTC nurses' capacity to develop trust-based relationships.

Results from Manuscript 2 (Chapter 3)

An innovative application of a video conferencing software application permitted the collection of real-time qualitative research data with volunteer participants while adhering to public health and institutional research guidelines and contact restrictions during the COVID-19 pandemic. Registered nurses in LTC with more than two years of clinical experience were recruited and enrolled to describe their experiences communicating with older adult residents and families regarding EOL care preferences and planning. Participants were individually interviewed virtually using the University of Minnesota's secure Zoom video conferencing software application following an interpretive phenomenological framework. Nurse participants were uniformly positive about the convenience, quality, interactivity and security of the virtual method of data gathering, perceiving no difference between their virtual and previous in-person interviews. Employing virtual video conferencing technology offers researchers and participants a safe, secure and effective method to gather qualitative data, even during a global pandemic. The benefits of a virtual, secure video conferencing research method include immediacy, convenience, interactivity, safety and security, while also presenting challenges from internet instability and limited presence. Suggestions were offered for conducting future virtual nursing qualitative research. With recent technological advances in video conferencing software and deployment of high-capacity wireless data networks,

virtual video conferencing could have a positive impact on the safety, convenience and immediacy of gathering data for future nursing research.

Results from Manuscript 3 (Chapter 4)

Ten LTC registered nurse participants with more the two years of clinical experience were individually interviewed regarding their experiences communicating with older adult residents and their families about EOL care planning following an interpretive phenomenological framework. The resultant data from their transcribed interviews were analyzed for thematic content employing Parse's Theory of Humanbecoming as a theoretical framework. The study found that four concepts: Being Together, Becoming, Compassionate Care and Unique Impact on Nurses, are all part of nurses' commitment to a continuous EOL care communication process with residents and their families. Nurses commit to this process throughout the evolving dynamic of EOL care in LTC so they may be proactive advocates for resident-centered, goal-concordant care. Nurses begin the process by forming close relationships with residents and families to build trust, which fosters mutual comprehension, collaboration and informs nurses' resident knowledge and advocacy for appropriate compassionate care. The EOL care communication process and relationships with residents affects LTC nurses deeply both professionally and personally. The continuous commitment process is proposed as a looping progression, beginning with nurses' role and purpose which grounds their EOL care communication and is the basis for their initiation of relationship building with residents and their families. Relationship building forms the trust and insight necessary for nurses to engage in continuous communication and assessment, which guides their

knowledge of and advocacy for residents' preferences. Nurses' experience of their role as resident advocates impacts and informs their role and purpose. Nurses in LTC learn this continuous process through EOL care experiences with residents and families. They do not perceive their nursing education adequately prepares them for the complex, multidimensional relationship process or provides them with the skills and knowledge to initiate or sustain EOL care communication. Further research is needed to evaluate the nature and interaction and relative contribution of the components that constitute the phenomenon of the EOL care communication process in LTC.

Contribution to Science

This body of work contributes to nursing knowledge about the facilitators and process of EOL care communication between registered nurses, residents and their families in LTC. Since nurses lead resident care in LTC, supporting them to guide ongoing EOL care communication may help overcome extant barriers to articulating and documenting residents' goals of care (Hanson & Henderson, 2000). Given that nurses in LTC lead care planning and management, communication for EOL care planning with residents and their families is an essential aspect of their professional role and purpose. Long-term care registered nurses' goal in EOL care communication is to understand residents' evolving preferences and goals from a whole-person perspective to ensure their residents receive goal-concordant EOL care. Registered nurses in LTC initiate the EOL care communication process by forming close, trust-based relationships with residents and families to facilitate mutual comprehension and collaboration. Nurses learn through experience to become proactive communicators with and advocates for residents,

overcoming systemic and individual obstacles. The dynamic nature of EOL care communication and the deep relationships they form with residents have personal and professional impacts on nurses. The benefits they experience include personal growth, satisfaction with and meaning from work, and appreciation for their longitudinal relationships with residents. They also experience burdens such as professional burnout and stress, grief and loss from resident deaths, as well as moral and ethical distress when resident-centered EOL care is not supported by residents' families, providers, or their LTC organization's leadership.

Organizational Policy Implications

There are LTC organizational policy implications from these findings. Organizational culture has a significant effect on EOL care communication (Hanson & Henderson, 2000). Nurses need organizational resources and support to become effective EOL care communicators (Majerovitz et al. 2009). However, a gap remains between planning and implementation of the EOL care communication process, thus LTC leadership needs to examine systemic, organizational and individual factors that impede progress (Beck et al., 2017). Systemic barriers and challenges including patient care workflow design, regulatory burdens, emphasis on financial performance and a lack of continuing education (Midtbust et al., 2018). Nurses want and need standardized practices for the EOL care communication processes, beginning at admission (Aasmul et al., 2018). Clinical and administrative LTC leaders also need to examine implicit cultural and practice norms that might be barriers to efficacious EOL care and communication (Barnato, 2017). LTC organizational culture can support nurses' EOL care

communication by implementing staffing policies that support continuity in nurse-resident care assignments, normalizing EOL care planning for all stakeholders and adopting a responsive approach to resident EOL care needs (Brazil et al., 2004).

Nursing Education Implications

Pre- and post-licensure clinician education on EOL care communication has demonstrated positive effects on their knowledge, attitude and skills, especially education that focuses on a values-based communication process, role play, EOL care communication initiation and decision aid technology (Chan et al., 2019)**.** Registered nurses in LTC perceive their pre-licensure education provides information on hospice and general patient communication skills but does not prepare them with skills for EOL care communication or resident and family relationships (Carman et al., 2016; Gillett et al., 2016)**.** Targeted education is needed to address these nursing practice knowledge deficits (Beck et al., 2017).

Results from this study and another (O'Conner-Von & Bennett, 2020) suggests that post-licensure LTC nurses want continuing education for EOL care communication that targets several key areas: (1) relationship-building and trust formation with residents and their family, including sustaining communication for comprehension and care planning, engaging family members constructively, coping with resident-family conflict and challenging family dynamics; (2) resident advocacy for goal-concordant care, including whole-person assessment and care planning; (3) best practices for interprofessional collaboration and documenting EOL care preferences; (4) integrating

spirituality, faith and culture into EOL care communication; and (5) self-care for grief and loss.

Nursing Practice Implications

Registered nurses in LTC place significant value on their experiential knowledge to become effective communicators with residents and their families regarding EOL care planning, separate and distinct from their learned knowledge (O'Conner-Von & Bennett, 2020). Acknowledging the role of clinical experience in acquiring EOL care communication skills proficiency, clinical practice may benefit from pairing early career LTC nurses with experienced, skillful nurses for mentoring and shadowing. Establishing a continuous EOL care communication process across the resident's life in LTC supports resident-centered EOL care and helps LTC nurses develop close, trust-based bonds with residents and families from admission onwards (Funk et al., 2018; Mayahara et al., 2018). Instituting and clarifying EOL care communication practice norms, responsibilities and standards for nurses, other LTC staff, residents, families and external providers (i.e. – hospice) are important facilitators for EOL care communication (Aasmul et al., 2018). Similarly, combining routine whole-person resident assessments with valid instruments that focus on resident-defined quality of care and palliative symptom control can improve resident and clinician satisfaction with EOL care (Klapwijk et al., 2020). Resident and family prognostic comprehension is a significant issue, yet LTC nurses' workflow hampers their efforts to address resident or family misconceptions about disease trajectories. Decision aids and information technology can efficiently increase resident

and family comprehension of medical treatment risks and benefits, as well as promote collaborative care planning (Cardona-Morrell et al., 2017).

Experienced nurses in LTC recognize the relational nature of EOL care communication (O'Conner-Von & Bennett, 2020). Thus, continuity in nurses' resident care assignments needs to be a priority in LTC clinical practice. Continuity of care fosters communication, comprehension and collaboration with residents and family (Majerovitz et al. 2009). Continuity aids communication with available family members throughout the resident's life in LTC, an important facilitator for many residents EOL care decision-making, especially with those who are cognitively impaired (Dening et al.2019; Klemmt et al., 2020). Supporting the establishment and maintenance of relational trust with residents' families through continuity increases the efficacy of EOL care communication (Cagle et al. 2017). Continuity also enables individualization of resident assessments and care plans, adapting them for specific needs and preferences (Ingravallo et al., 2018). Finally, EOL care communication is challenging and demanding for LTC nurses with its attendant grief and added stress (Kaasalainen et al., 2007). Registered nurses need ongoing, tangible self-care resources and peer support to cope with the effects of EOL care communication, and cumulative grief and loss of resident relationships (O'Conner-Von & Bennett, 2020).

Nursing Research Implications

Current EOL care communication research focuses on discrete elements of communication and advance care planning documentation interventions instead of an inclusive, systems evaluation approach that recognizes the process's complexity,

contextual factors and impacts on all stakeholders (Jimenez et al., 2019). Designing valid methods to evaluate multiple communication components, and reliably measuring their relative contributions over time are both complex challenges (Hickman et al. 2019). Given that methodological heterogeneity and weaknesses compromise the validity of extant EOL care communication interventions or synthesis of their results, coordination around a consistent conceptual framework and standardization of research methods is required for meaningful comparisons of different approaches to EOL care communication (Bennett & O'Conner-Von, 2020; Johnson et al., 2018).

There is a lack of research on EOL care education and communication for low socioeconomic status, low education level and nonwhite residents and families (Hickman & Pinto, 2014). Communication interventions for EOL care planning and advance care planning have generally been developed by and targeted at persons who identify with a Caucasian-centric culture based on the ethic of patient autonomy (Sanders et al., 2016). Future research can examine the effects of culturally attenuated advance care planning and EOL care communication interventions for multiple cultural orientations (Partain et al., 2017). Research that focuses on EOL care communication and education for underserved populations may help address these health disparities (Krishnan et al., 2017).

Conclusion

There is a significant gap in qualitative research knowledge regarding registered nurses in LTC communication with residents and families about EOL care preferences. This gap negatively impacts residents' EOL care satisfaction, outcomes and nurses' resiliency. A qualitative research study employing an interpretive phenomenological

framework was conducted through virtual individual interviews with ten registered nurses in urban, suburban and rural LTC settings. This study found that experienced registered nurses in LTC embrace their role and responsibility as leaders for EOL care communication and planning. They view EOL care communication as central to their purpose as compassionate, proactive advocates for residents. Registered nurses in LTC work diligently and creatively to overcome existing barriers and obstacles to ensure residents receive goal-concordant EOL care, investing in both relational and instrumental care with residents and families. They describe the deep, close relationships they form with residents and families over time as akin to caring for a family member. Registered nurses in LTC form close, trust-based relationships with residents and families as the foundation for engaging in EOL care communication. Due to the dynamic, evolving nature of EOL care in LTC settings, registered nurses perform ongoing resident assessments from a whole-person perspective, adapting and individualizing communication strategies to account for resident and family physical, mental, social and cultural differences. Their close, longitudinal relationships with residents and the EOL care communication process affect nurses in LTC positively and negatively. The benefits they experience include personal growth, satisfaction with and meaning from work, and appreciation for their close, family-like relationships with residents. They also experience burdens including professional burnout and stress, individual and cumulative grief and loss from resident deaths, as well as moral and ethical distress when resident-centered EOL care is not supported by residents' families, providers, or their LTC organization's leadership.

Communication in LTC to discern and articulate residents' EOL care preferences is complex, multicomponent and dynamic. Registered nurses in LTC developed knowledge and skills with EOL care communication are experientially derived. They do not perceive their learned knowledge from pre- or post-licensure nursing education adequately prepares them for EOL care communication in LTC settings. Incorporating experienced registered nurses' expertise and knowledge about effective EOL care communication with residents and families into nursing education, clinical practice guidelines, organizational policy, workflow design and communication intervention design can promote resident-centered EOL care and nurses' resiliency. Implications were noted for nursing research, education, practice and organizational policies that can support LTC registered nurses' EOL care communication to ensure resident-centered, goal-concordant EOL care, as well as enhancing nurses' resiliency. These findings are significant due to the current, pressing need to understand the facilitators and process that experienced LTC RNs use to overcome obstacles to effective EOL care communication. Future research must consider a holistic approach to evaluating EOL care communication efficacy to account for the complex, relational, dynamic nature of EOL care communication in LTC.

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Appendix A - Study Protocol

PROTOCOL COVER PAGE

Protocol Title	Long-term care nurses' experiences with EOL care communication with patients and families
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Scientific Assessment	I believe Scientific Assessment is not required.
Version Number/Date:	1.0 6/15/20

REVISION HISTORY

Revision #	Version Date	Summary of Changes	Consent Change?
2.0	6/15/20	Add language to reflect interviews will be conducted via a secure Zoom application	Yes

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ABBREVIATIONS/DEFINITIONS

Definitions used in this protocol

- Patients are seriously ill persons with at least 1 advanced stage disease or multimorbidity frailty.
- Family is the social group, including surrogates, designated by the patient to make their health care decisions if they became incapacitated.
- End-of-life refers to the timespan from weeks to years that patients live in a state of declining health.
- Long-term care refers to temporary or permanent residential healthcare facilities, including skilled nursing, memory care, assisted living, residential care and homes for the aged.
- End-of-life care communication is an iterative discursive process between nurses, patients and their families to clarify and document treatment choices and preferences to guide a patient's care as the end-of-life approaches or they become incapacitated. End-of-life care communication is a shared decision-making relational process to reach consensus about a patient's future care choices and preferences, informed by that patient's values and goals.

Abbreviations used in this protocol.

- LTC = Long-term care
- EOL = end-of-life

1.0 Objectives

1.1 Purpose: Describe the experience of nurses in LTC with more than 2 years' practice in skilled nursing, assisted living or memory care about communicating with patients, families and surrogates about EOL care preferences and choices to improve shared decision-making, patient-centered EOL care and increase the likelihood of that patients' EOL care received is concordant with patients' goals.

2.0 Background

2.1 Significance of Research Question/Purpose: Due to their unique professional role, proximity to and relationship with residential patients, LTC nurses are a critical nexus for communication about EOL care with patients, their families and surrogate decision-makers. Communication about EOL care planning includes, but is not limited to, advanced directive documentation arising from advanced care planning discussions facilitated by LTC nurses. Advanced care planning, driven by patients' goals, values and preferences, is a subset of goal-concordant care, which increases the probability of achieving patient-centered care outcomes. Under the Center for Medicare & Medicaid Services' 2017 regulations, LTC facilities are required to provide advanced care planning services to all their patients.[1] Yet, it is estimated that less than 50% of the current 2.1 million LTC patients in the United States have completed an advanced directive.[2,3] Communication for EOL care planning between healthcare professionals is associated with higher rates of advanced directive documentation[3]. Efficacious interventions' for EOL care planning in LTC are associated with nurses' accumulated experience and willingness to initiate these discussions.[4-6] Though nurses in LTC settings are crucial to communication about EOL care planning, they face multiple barriers to EOL care communication, including time constraints, lack of training and fragmented communication patterns.[5-9] There is a gap between the identified need for EOL care planning communication in LTC, and the nurses' capacity to initiate or sustain these discussions.[3,4,6] This gap has significant consequences for all stakeholders in LTC, negatively impacting patients' quality of care, patient and family or surrogate satisfaction with EOL care and nurses' work satisfaction and resiliency.[3,8-11] The efficacy of advanced care planning interventions' in LTC have been reported in the literature.[4,9-13] However, there is a lack of qualitative descriptive knowledge of nurses' experience in LTC regarding EOL care discussions with patients and families. Thus, it is proposed to interview registered nurses in LTC to describe their experiences initiating and sustaining EOL care discussions with patients and families. The long-term goal of this research is to improve outcomes and satisfaction with EOL care in LTC by

understanding how nurses in LTC overcome existing individual and systemic barriers to lead EOL care communication. Communication regarding EOL care may improve shared decision-making, patient-centered EOL care and increase the likelihood of goal-concordant care. Patients in LTC, their families and surrogates need timely, relevant information and support to understand the relative risks and benefits of their EOL care options and communicate their preferences and decisions.[7,14] However, LTC patients and their families are reluctant to initiate EOL care discussions, waiting for clinicians to initiate them[15]. There is a positive association between LTC clinical experience and patient or family satisfaction with EOL care communication.[16-19] This study's rationale is that describing LTC nurses' experience could inform future EOL care education for LTC nurses, enhance their capacity to develop trust-based relationships with patients essential to EOL care discussions, and improve the efficacy of current EOL care communication interventions in LTC.[20,21] This research is significant because EOL care communication with patients, families and surrogates is challenging for nurses to initiate and sustain.[22] Though the U.S. LTC patient population is projected increase significantly,[2] few U.S. adults have engaged in EOL care planning discussions with each other or their providers, despite prevalent negative views of EOL care outcomes and satisfaction in all care settings.[3,23] There is a current, pressing need to understand the facilitators and process that experienced LTC nurses use to initiate and sustain EOL care communication. Explicating these facilitators and process will support the design of education and interventions for LTC nurses about EOL care communication, potentially increasing patient-centered, goal-concordant EOL care and patient EOL care satisfaction and may also improve the efficacy of current EOL care communication interventions.[20,21]

2.2 Preliminary Data: The feasibility of EOL care planning communication interventions between patients, families and healthcare professionals in LTC settings has been demonstrated.[4] Nurse-patient communication for EOL care planning qualitative research reported in the literature has focused on acute and community nursing settings.[7, 16- 20, 24, 25] Qualitative research in LTC has demonstrated feasibility of gathering evidence from nurses and patients about their respective EOL care experiences,[21, 26] but none have focused on their dyadic communication process from the nurse's perspective. Nurses in LTC who participated in a 2019 focus group study, co-conducted by the student and principal investigators, described the communication strategies and practices they developed through experience to clarify EOL care preferences with patients, their families and interdisciplinary colleagues.[27] These nurses reported that initiating and sustaining EOL care communication with patients and families was exacting, and their commitment to patient advocacy and

collaboration with all stakeholders challenged them.[27] They observed that years of clinical practice were needed to acquire sufficient EOL care communication experience and skills due inadequate education or preparation to assess patients' and families' comprehension and collaborate with them.[27]

2.3 Existing Literature: Patient family and surrogate satisfaction with the quality and goal-concordance of EOL care are both associated with communication about patient EOL care preferences and choices.[4,6,7,22,23] Nurse job satisfaction and resiliency are also associated with communication about EOL care and goal-concordant patient care.[5,7,19,20] Advanced care planning has become the standard protocol in LTC for documenting patient EOL care goals and preferences.[3,8,13] Qualitative research studies of nurse-patient communication for EOL care planning have been reported in the literature in acute and community settings.[7,16-20,24,25]

3.0 Study Endpoints/Events/Outcomes

3.1 Primary Endpoint/Event/Outcome: The short-term objective of this study is to describe and interpret LTC nurses' descriptions of their experience of EOL care communication with patients and families. This proposed study will use an interpretive phenomenological interview methodology within a constructionist framework to interview Minnesota-based LTC registered nurses with at least 2 years of clinical experience.

3.2 Secondary Endpoint(s)/Event(s)/Outcome(s): N/A.

4.0 Study Intervention(s)/Interaction(s)

4.1 Description: For this study, each LTC nurse participant interview will be conducted by the student investigator following Van Manen's interpretive phenomenological interviewing guidelines,[30] for up to 90 minutes per interview. Van Manen's guidelines use interview participant's' lived experience to constitute the phenomenon, elucidating participants' description of their experientially developed knowledge and the meaning they attach to this knowledge.

5.0 Procedures Involved

5.1 Study Design: This study's qualitative research framework is interpretive, or hermeneutic phenomenology, a systematic, intersubjective study of individuals making meaning from their lived experience.[28] Grounded in a constructivism framework, this study seeks to understand LTC nurses' developed knowledge and attributed meaning from their experience communicating with patients, families and surrogate decision-makers about EOL care planning through phenomenological interviews.[29] Constructivism is the appropriate framework to analyze LTC nurses' language descriptions construction of their lived experience.[29]

5.2 Study Procedures: Interviews will be scheduled and conducted at the convenience of each LTC nurse participant's schedule via a secure U of Minnesota's Zoom teleconferencing application, to minimize participant burden, increase their ease and comfort with the interview process, assure participant privacy and confidentiality, and reduce potential distractions. A modest financial incentive will be offered to each participant to compensate them for their time. Three days before the mutually agreed upon date and time for their interview, each participant will receive a letter outlining the date, time and place for the interview, a summary of the study protocols and procedures, including informed consent, and their initial demographic questions to be completed prior to each interview (see below). The evening before the interview each participant will receive a confirming phone call and email from the student investigator reminding them of their interview details and affirmation that they have downloaded the Zoom application to the device they are using for this interview. Each participant interview will begin with the student investigator reviewing a summary of study protocols and procedures with the participant, including reaffirming participant voluntary informed consent, confidentiality and anonymity in all digital recordings and transcripts and data security. Each interview is expected to take up to 90 minutes, using seven interview questions designed to focus the interview on the phenomena of interest (see below). Each interview will be conducted by the student investigator for this study, following interpretive phenomenological interviewing guidelines.[30,31] As the interview progresses, the student investigator will use short probes, based on participants' descriptions of their experience, to clarify their knowledge, or redirect participants back to the phenomena of interest. Two redundant digital audio devices will simultaneously record each interview. All Zoom video and digital audio recordings will be professionally transcribed by a University of Minnesota School of Nursing private contractor with substantial experience in transcribing audio and Zoom video qualitative research interview data. The student investigator will review all interview transcriptions to verify their fidelity versus relevant audio recordings for quality assurance. The student investigator will record his own reflexive journal notes after each interview and use these as part of the data analysis process. An interview guide will be created by the student investigator and used for all interviews to ensure each participant receives the same informed consent and enrollment procedures, as well as adherence to the interview process.[30,31] Participants will be enrolled and interviewed until transcribed textual data and interviewer field notes indicate sufficient data has been generated to achieve saturation. Saturation will be reached when the language content of interviews does not reveal any novel data for context or setting.

Initial demographic questions for participants to be completed before their interview	
Your Age	
Your Sex: M/F	
Your Nursing Education: Associate: ___ Baccalaureate:___ Masters: ____	
Your Nursing Education Institutions(s)	
Your Total Nursing Experience (years)	
Your Total LTC Nursing Experience (years): ___ SNF ___ TCU ___ Memory Care ___ ALF	
Your Other Clinical RN Experience (years): ___ Acute ___ Rehab ___ Home ___ Clinic ___ Hospice	
Your Workplace/Facility Setting: ___Urban __Rural __ Suburban	
What do you remember learning about caring for patients approaching the end of life in your nursing education?	
Where and when did you learn this?	
What do you remember learning about communicating with patients and their families regarding end of life care in your nursing education?	
Where and when did you learn this?	
Briefly describe the amount and delivery of your continuing education on end-of-life care within your LTC workplace(s)? (i.e. – in-service, conferences, SharePoint, journals, web, etc.)	

Interview Questions for Nurses in Long-Term Care: Experience with Patients & Families Communicating About End-Of-Life Care Preferences & Goals

1. I'm interested in hearing about your experiences in LTC communicating with over the entire time a patient is in your facility: weeks, months, even years. Think back to a recent experience that you had with a patient or family about end-of-life care discussions. Please describe it.

2. Please describe both a positive and negative experience with patients and families about end-of-life care discussions with and surrogates about end-of-life care preferences, and goals?

3. What have you found helps you know start, and keep these discussions going?

4. How do you know when you have discovered enough information about the patient's goals, preferences and values for an end-of-life care plan?

5. Please give an example, or two, of a time when you overcame obstacles to communicating with patients and families? What were the obstacles and how did you overcome them?

6. What advice would you have for new nurses just getting started in long-term care about communication with patients and families about end-of-life care preferences?

7. What have I not asked you about when it comes to communication with patients and families about end-of-life care preferences?

5.3 Follow-Up: Study participants will subsequently have an opportunity to review a summary of their transcribed interview to offer feedback, provide clarification on language and meaning or stimulate additional contributions to their interview data from their experience.

5.4 Individually Identifiable Health Information: N/A

6.0 Data Banking: N/A

7.0 Sharing of Results with Participants

Study participants will have the option of receiving a copy of the Results section of the resultant dissertation.

8.0 Study Duration

It is anticipated that individual participant's participation in the study will be for up to 90 minutes, with the option of participating in a subsequent review of a summary of their transcribed interview so they can offer feedback, provide clarification on language and meaning, or stimulate additional contributions to their interview data from their experience for up to 30 minutes.

It is anticipated that the duration for all participants to complete participation in the study will be within 90 days.

It is anticipated that all study procedures and data analysis will be completed within 180 days.

9.0 Study Population

9.1 Inclusion Criteria: Participants must meet the following criteria for inclusion in the study:

- Age ≥ 21 years
- Have > 2 years of long-term care nursing experience
- Be registered or baccalaureate-prepared nurses
- Be ≥ 0.5 FTE employees of Tealwood Senior Living long-term care facilities
- Be able to participate in at least one 90-minute interview with student investigator
- Be willing to discuss their experience communicating with patients and families about end-of-life care planning
- Be able to speak and read English
- Be able to provide informed consent for study participation

9.2 Exclusion Criteria: Participants will be excluded from the study if they have:

- Have ≤ 2 years of long-term care nursing experience
- Are ≤ 0.5 FTE employees of Tealwood Senior Living long-term care facilities

9.3 Screening: Individuals will be screened for eligibility through recruitment materials and enrollment procedures.

10.0 Vulnerable Populations

10.1 Vulnerable Populations:

Population / Group	Identify whether any of the following populations will be targeted, included (not necessarily targeted) or excluded from participation in the study.
Children	Excluded from Participation
Pregnant women/fetuses/neonates	Excluded from Participation
Prisoners	Excluded from Participation
Adults lacking capacity to consent and/or adults with diminished capacity to consent, including, but not limited to, those with acute medical conditions, psychiatric disorders, neurologic disorders, developmental disorders, and behavioral disorders	Excluded from Participation
Non-English speakers	Excluded from Participation
Those unable to read (illiterate)	Excluded from Participation
Employees of the researcher	Excluded from Participation
Students of the researcher	Excluded from Participation
Undervalued or disenfranchised social group	Excluded from Participation

Active members of the military (service members), DoD personnel (including civilian employees)	Excluded from Participation
Individual or group that is approached for participation in research during a stressful situation such as emergency room setting, childbirth (labor), etc.	Excluded from Participation
Individual or group that is disadvantaged in the distribution of social goods and services such as income, housing, or healthcare.	Excluded from Participation
Individual or group with a serious health condition for which there are no satisfactory standard treatments.	Excluded from Participation
Individual or group with a fear of negative consequences for not participating in the research (e.g. institutionalization, deportation, disclosure of stigmatizing behavior).	Excluded from Participation
Any other circumstance/dynamic that could increase vulnerability to coercion or exploitation that might influence consent to research or decision to continue in research.	Excluded from Participation

10.2 Additional Safeguards:

11.0 Number of Participants

11.1 Number of Participants to be Consented: Given previous phenomenological interview studies about nurse-patient communication,[18] it is estimated that a sample of 8-12 participants from a LTC nurse population will be required to achieve interview data saturation. If this sample size does not produce sufficient data for saturation, this study will have the flexibility to interview additional eligible LTC nurses until saturation is achieved

11.2 Recruitment Methods: Individual recruitment of LTC nurse participants will occur through nomination by Tealwood clinical care staff of potential nurse participants, and electronic recruitment notices to nominees. Recruitment will emphasize this study's potential research benefits: (1) the opportunity to explore and describe their experience of EOL care communication with patients, families and surrogates; and (2) insights and developed knowledge from their experience will be disseminated and shared with other nurses, contributing to the breadth and depth of LTC nursing knowledge and science.

11.3 Recruitment Process: Individual recruitment of LTC nurse participants will occur through nomination by Tealwood clinical care staff of potential nurse participants, and electronic recruitment notices to nominees. Eligible nurse participants who respond positively will be enrolled through either in-person or telephonic presentation due to the sensitivity of the topic of EOL care communication topic, subject to participants' voluntary informed consent. The informed consent procedure will include: (1) introducing the purpose of the study and affiliation with the University of Minnesota School of Nursing; (2) the study's data safety and management protocols to assure participant's confidentiality through de-identification procedures, secure data storage, and adherence to qualitative research ethical guidelines; (3) participant's voluntary participation and disclosure of the initial interview questions

11.4 Source of Participants: : The supporting partner for this study is Tealwood Senior Living (Tealwood) is a private Minnesota-based LTC organization that owns or manages more than 20 LTC facilities. Tealwood will support participant recruitment, enrollment and interviews.

11.5 Identification of Potential Participants: The supporting partner for this study is Tealwood Senior Living (Tealwood) is a private Minnesota-based LTC organization that owns or manages more than 20 LTC facilities. Tealwood will support participant recruitment, enrollment and interviews.

11.6 Recruitment Materials: Recruitment materials are a study flyer electronically delivered to nominated nurse participants with the support of Tealwood.

11.7 Payment: A modest financial incentive of $50 gift card to a local business will be offered to each participant to compensate them for their time at the

end of their interview. This incentive will paid for out of the student investigator's personal funds.

11.8 Withdrawal of Participants: Participation in this study is voluntary and participant's decision whether or not they choose to participate is solely their own choice. Participants will not be required to answer any questions and may choose to end their participation at any time during the interview without explanation or penalty.

11.9 Withdrawal Circumstances: Participants will not be required to answer any questions and could choose to end their participation at any time during the interview.

11.10 Withdrawal Procedures: Data collection for a participant will cease upon their withdrawal.

11.11 Termination Procedures: The student investigator may analyze the data collected for participant interviews that have been terminated.

12.0 Risks to Participants

12.1 There are no known risks or benefits for participation in this study.

12.2 Foreseeable Risks: There is very modest risk of necessary medical interventions associated with qualitative interviews. The participants will all be experienced registered nurses. The student investigator will follow all relevant facility safety precautions in the event that medical intervention is necessary for adverse events. There is little risk of breach of confidentiality since study participants will not be providing identifying information such as name, address, telephone number or date of birth.

12.3 Reproduction Risks: N/A

12.4 Risks to Others: N/A

13.0 Incomplete Disclosure or Deception

13.1 Incomplete Disclosure or Deception: N/A

14.0 Potential Benefits to Participants

14.1 Potential Benefits: Participants may directly benefit from the opportunity to explore and describe their experience of EOL care communication with patients and families, as well as gain insight and develop knowledge from their experience

15.0 Statistical Considerations

15.1 Data Analysis Plan: Employing an interpretive/hermeneutic approach, textual transcriptions and audio recordings of all participant interviews will be analyzed to identify categories and themes from the participants' language. The student investigator will conduct the qualitative data analysis with oversight by the PI, analyzing the interview data for

participants' developed knowledge and attributed meaning from their experience of what, how, when, where and with whom they communicate about EOL care planning. In coding participants' language, the student investigator will pay close attention to participants' descriptions of their consequential actions, antecedent motivations, attitudes, values, beliefs, explicit and implicit knowledge. Version 12 of NVivo qualitative data analysis software will be used under the University of Minnesota's institutional license for initial coding, visualization and categorization of textual transcribed data. The student investigator will analyze coded and categorized data from participants' language. This analysis will include their descriptions of successful EOL care discussions and its facilitators, with patients, families and surrogates, along with their developed knowledge and insight over time. These analytical findings will be organized and categorized using interpretive, or hermeneutic principles with verbatim quotes from the data that illustrate and faithfully represent the participant's language.[28,30] To identify core meanings of the participants' experience and capture the phenomenon, the PI's data analysis will focus on essential themes that are both critical and unique to the phenomenon of EOL care planning communication, as opposed to incidental themes. Language from the student investigator's reflexive journaling will also be analyzed to incorporate the co-creation of meaning that occurs between interviewer and participant during interpretive phenomenological interviews.[29, 31]
Power Analysis: N/A

Statistical Analysis: N/A

15.1 Data Integrity: To ensure data integrity and confidentiality, each study participant will be de-identified through assignment of a unique code name consisting of numbers and letters. Code names will be used for all data collection purposes, which will be kept in an electronic, password protected database and only accessed by the student investigator. No identifying information will be provided in any files. Electronic data files will be stored on a secure University of Minnesota School of Nursing server that can only be accessed with a University login ID and password by individuals to whom the study the student investigator has granted access.

16.0 Health Information and Privacy Compliance

16.1 Select which of the following is applicable to your research:

☒ My research does not require access to individual health information and therefore assert HIPAA does not apply.

☐ I am requesting that all research participants sign a HIPCO approved HIPAA

Disclosure Authorization to participate in the research (either the standalone form or the combined consent and HIPAA Authorization).

☐ I am requesting the IRB to approve a Waiver or an alteration of research participant authorization to participate in the research.

Appropriate Use for Research: Only data collected from voluntary nurse participant interviews will be used for this study.

☐ An external IRB (e.g. Advarra) is reviewing and we are requesting use of the authorization language embedded in the template consent form in lieu of the U of M stand-alone HIPAA Authorization. Note: External IRB must be serving as the privacy board for this option.

16.2 Identify the source of Private Health Information you will be using for your research (Check all that apply)

☐ I will use the Informatics Consulting Services (ICS) available through CTSI (also referred to as the University's Information Exchange (IE) or data shelter) to pull records for me

☒ I will collect information directly from research participants.

☐ I will use University services to access and retrieve records from the Bone Marrow Transplant (BMPT) database, also known as the HSCT (Hematopoietic Stem Cell Transplant) database.

☐ I will pull records directly from EPIC.

☐ I will retrieve record directly from axiUm / MiPACS

☐ I will receive data from the Center for Medicare/Medicaid Services

☐ I will receive a limited data set from another institution

☐ Other. Describe:

16.3 Explain how you will ensure that only records of patients who have agreed to have their information used for research will be reviewed.

N/A

16.4 Approximate number of records required for review:

N/A

16.5 Please describe how you will communicate with research participants during the course of this research. Check all applicable boxes

☐ This research involves record review only. There will be no communication with research participants.

☐ Communication with research participants will take place in the course of treatment, through MyChart, or other similar forms of communication used with patients receiving treatment.

☒ Communication with research participants will take place outside of treatment settings. If this box is selected, please describe the type of communication and how it will be received by participants.

16.6 Access to participants

16.7 Location(s) of storage, sharing and analysis of research data, including any links to research data (check all that apply).

☐ In the data shelter of the Information Exchange (IE)

☐ Store ☐ Analyze ☐ Share

☐ In the Bone Marrow Transplant (BMT) database, also known as the HSCT (Hematopoietic Stem Cell Transplant) Database

☐ Store ☐ Analyze ☐ Share

☐ In REDCap (recap.ahc.umn.edu)

☐ Store ☐ Analyze ☐ Share

☐ In Qualtrics (qualtrics.umn.edu)

☐ Store ☐ Analyze ☐ Share

☐ In OnCore (oncore.umn.edu)

☐ Store ☐ Analyze ☐ Share

☒ In the University's Box Secure Storage (box.umn.edu)

☒ Store ☒ Analyze ☐ Share

☐ In an AHC-IS supported server. Provide folder path, location of server and IT Support Contact:

☐ Store ☐ Analyze ☐ Share

☐ In an AHC-IS supported desktop or laptop.

Provide UMN device numbers of all devices:

☐ Store ☐ Analyze ☐ Share

☐ Other.

Indicate if data will be collected, downloaded, accessed, shared or stored using a server, desktop, laptop, external drive or mobile device (including a tablet computer such as an iPad or a smartform (iPhone or Android devices) that you have not already identified in the preceding questions

☐I will use a server not previously listed to collect/download research data

☒I will use my personal, secure MacBook laptop not previously listed

☐I will use an external hard drive or USB drive ("flash" or "thumb" drives) not previously listed

☐I will use a mobile device such as a tablet or smartphone not previously listed

16.8 Vendors. Tybee Types, a School of Nursing vendor for many years will transcribe participant Interview Zoom recordings

16.9 Links to identifiable data: N/A

16.10 Sharing of Data with Research Team Members. N/A

16.11 Storage and Disposal of Paper Documents: Any paper documents generated as a result of this research project will be disposed of by secure School of Nursing document shredding services.

17.0 Confidentiality

17.1 Data Security: To ensure data security, each study participant will be de-identified through assignment of a unique code name consisting of numbers and letters. Code names will be used for all data collection purposes, which will be kept in an electronic, password protected database and only accessed by the student investigator. No identifying information will be provided in any files. Electronic data files will be stored on a secure University of Minnesota School of Nursing server that can only be accessed with a University login ID and password by individuals to whom the study student investigator has granted access.

18.0 Provisions to Monitor the Data to Ensure the Safety of Participants
The proposed research is not a clinical trial.

18.1 Data Integrity Monitoring. To ensure data security, each study participant will be de-identified through assignment of a unique code name consisting of numbers and letters. Code names will be used for all data collection purposes, which will be kept in an electronic, password protected database and only accessed by the student investigator. No identifying information will be provided in any files. Electronic data files will be stored on a

secure University of Minnesota School of Nursing server that can only be accessed with a University login ID and password by individuals to whom the study student investigator has granted access.

18.2 Data Safety Monitoring: To ensure data security, each study participant will be de-identified through assignment of a unique code name consisting of numbers and letters. Code names will be used for all data collection purposes, which will be kept in an electronic, password protected database and only accessed by the student investigator. No identifying information will be provided in any files. Electronic data files will be stored on a secure University of Minnesota School of Nursing server that can only be accessed with a University login ID and password by individuals to whom the study student investigator has granted access.

19.0 Compensation for Research-Related Injury

19.1 Compensation for Research-Related Injury: N/A

19.2 Contract Language: N/A

20.0 Consent Process

20.1 Consent Process (when consent will be obtained): Prior to initiation of each interview, participants that meet eligibility criteria, the student investigator will review participants' voluntary informed consent. Informed consent procedures include: (1) introducing the purpose of the study, the researcher/interviewer's background and affiliation with the University of Minnesota; (2) study protocol and procedures to assure participant confidentiality and safety, data integrity, and ethical guidelines; (3) and initial interview questions. Each participant will sign the consent form and have their signature witnessed prior to commencement of their interview.

20.2 Waiver or Alteration of Consent Process (when consent will not be obtained, required information will not be disclosed, or the research involves deception): N/A

20.3 Waiver of Written/Signed Documentation of Consent (when written/signed consent will not be obtained): N/A

20.4 Non-English Speaking Participants: N/A.

20.5 Participants Who Are Not Yet Adults (infants, children, teenagers under 18 years of age): N/A

20.6 Cognitively Impaired Adults, or adults with fluctuating or diminished capacity to consent: N/A

20.7 Adults Unable to Consent: N/A

21.0 Setting

21.1 Research Sites: The supporting partner for this study is Tealwood Senior Living, a private Minnesota-based LTC organization that owns or manages more than 20 LTC facilities. Tealwood will support participant recruitment, enrollment and interviews.

21.2 International Research: N/A

21.3 Community Based Participatory Research: N/A

21.4 Multi-Site Research: N/A

21.5 Study-Wide Number of Participants: Anticipated = 12

21.6 Study-Wide Recruitment Methods: N/A

21.7 Study-Wide Recruitment Materials: N/A

21.8 Communication Among Sites: N/A

21.9 Communication to Sites: N/A

22.0 Coordinating Center Research: N/A

23.0 Resources Available

23.1 Resources Available:

- The principal investigator is the student investigator's PhD. advisor and will meet on a regular basis with the student investigator to evaluate progress and provide support.
- Tealwood Senior Living owns or manages more than 20 LT facilities in Minnesota and adjacent states and employs more than 50 LTC nurses.
- This study is the student investigator's dissertation research and he will devote his full time to it until completion. The student investigator has completed all PhD. coursework and is not employed at the present time.
- The student investigator has access to all the facilities, resources and support of the School of Nursing PhD. program.
- All participants will sign their informed consent form and have their signature witnessed.

24.0 References

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Appendix B – Participant Consent Letter

August __, 2020

Dear _____,

Re: Consent to participate in a nursing research interview

You are invited to participate in a nursing research interview study focusing on your experience communicating with long-term care residents and their families about the resident's end-of-life care preferences and choices. The purpose of this study is to describe the communication process nurses in long-term care use to start and sustain discussions about end-of-life care with seriously ill residents, their families and surrogate decision-makers. Nurses in long-term care learn through their experience how to overcome obstacles to having these complex, sensitive discussions in order to learn enough to provide care that is consistent with residents' goals of care.

The results of this study will provide valuable information to shape future nursing education, training in long-term care, and improve the effectiveness of current efforts to communicate effectively with residents and families. You were selected because Tealwood Senior Living nursing leadership identified you as a nurse with valuable insight and experience in this area.

This study is being conducted by Dr. Susan O'Conner-Von, University of Minnesota School of Nursing and Frank Bennett, a graduate student researcher and Ph.D. candidate.

Participation in this study is voluntary. Your decision about whether or not you choose to participate will not affect your current or future relationship with Tealwood Senior Living. There are no known risks or benefits for participation in this study. The interview should take up to 90 minutes to complete and will be conducted by secure videoconferencing at a time and date convenient for you. Participants will receive a modest financial token of appreciation as compensation for their time and participation. You will not be required to answer any questions and you may choose to end your participation at any time during the interview without explanation or penalty.

Though the interviews will be recorded, your identity will not be recorded should you choose to participate. All participant data from this study will be de-identified and stored securely, with only Dr. Susan O'Conner-Von and Frank Bennett having access to the data. Additionally, the identity of any resident, family member or staff member mentioned in your interview will also be deidentified. Any reports, published or not, will not include any information that would make it possible to identify you. After the study is completed, all data including the video recordings will be destroyed. If you have any questions or concerns, please contact either Dr. Susan O'Conner-Von, (651) 230-0890 (email: ocon0025@umn.edu), or Frank Bennett, (612) 940-3372 (email: fbennett@umn.edu). We ask that you send us an email at the end of your interview acknowledging your consent to this recorded interview.

This research study has been reviewed and approved by an Institutional Review Board (IRB) within the Human Research Protections Program (HRPP) at the University of Minnesota. If you have concerns that you do not wish to share with the researchers, call the Research Participants' Advocate Line at (612) 624-4490 or go to www.irb.umn.edu/report.html. You are encouraged to contact the HRPP if your questions, concerns, or complaints are not being answered by the research team, you cannot reach the research team, you want to talk to someone besides the research team, you have questions about your rights as a research subject, or you want to get information or provide input about this research.

We sincerely thank you for your time,

Dr. Susan O'Conner-Von & Frank Bennett

Appendix C - Participant Recruitment Flyer

UNIVERSITY OF MINNESOTA

School of Nursing

Driven to Discover℠

Nursing Research Interview

We are conducting individual interviews (up to 90 minutes, as needed) with volunteer long-term care registered nurses about their experiences communicating with patients and families about end-of-life care preferences and choices. At completion of the interview, each participant will receive a $50 gift card toward compensation for their time.

You are eligible to participate if you:

- Are a registered nurse
- Work at least 0.5 FTE
- Have worked in long-term care for more than 2 years

Location:

Each individual interview will be scheduled at a time and date arranged according to each participant's schedule. Interviews will be conducted remotely by secure video conferencing to ensure participants' safety and convenience

Please contact us if you're interested in participating or to learn more about the study:

Frank Bennett: fbennett@umn.edu (612)-940-3372

Dr. Susan O'Conner-Von: ocon0025@umn.edu (651) 230-0890

This study, #9947, has been approved by University of Minnesota Institutional Review Board (7/20/20)

Appendix D - Participant demographic questionnaire

Initial demographic questions for participants to be completed before their interview
Your Age
Your Sex: M/F
Your Nursing Education: Associate: ___ Baccalaureate:___ Masters: ____
Your Nursing Education Institutions(s)
Your Total Nursing Experience (years)
Your Total LTC Nursing Experience (years): ___ SNF ___ TCU ___ Memory Care ___ ALF
Your Other Clinical RN Experience (years): ___ Acute ___ Rehab ___ Home ___ Clinic ___ Hospice
Your Workplace/Facility Setting: ___Urban __Rural __ Suburban
What do you remember learning about caring for patients approaching the end of life in your nursing education?
Where and when did you learn this?
What do you remember learning about communicating with patients and their families regarding end of life care in your nursing education?
Where and when did you learn this?
Briefly describe the amount and delivery of your continuing education on end-of-life care within your LTC workplace(s)? (i.e. – in-service, conferences, SharePoint, journals, web, etc.)

Appendix E – Participant initial interview questions

Interview Questions for Nurses in Long-Term Care: Experience with Patients & Families Communicating About End-Of-Life Care Preferences & Goals

1. I'm interested in hearing about your experiences in LTC communicating with over the entire time a patient is in your facility: weeks, months, even years. Think back to a recent experience that you had with a patient or family about end-of-life care discussions. Please describe it.

2. Please describe both a positive and negative experience with patients and families about end-of-life care discussions with and surrogates about end-of-life care preferences, and goals?

3. What have you found helps you know start, and keep these discussions going?

4. How do you know when you have discovered enough information about the patient's goals, preferences and values for an end-of-life care plan?

5. Please give an example, or two, of a time when you overcame obstacles to communicating with patients and families? What were the obstacles and how did you overcome them?

6. What advice would you have for new nurses just getting started in long-term care about communication with patients and families about end-of-life care preferences?

7. What have I not asked you about when it comes to communication with patients and families about end-of-life care preferences?

Appendix F: University of Minnesota IRB Approval

UNIVERSITY OF MINNESOTA

Twin Cities Campus

Human Research Protection Program
Office of the Vice President for Research

Room 350-2
McNamara Alumni Center
200 Oak Street S.E.
Minneapolis, MN 55455

612-626-5654
irb@umn.edu
https://research.umn.edu/units/irb

IMPORTANT: All human research conducted at the University of Minnesota must adhere to the IRB guidance and requirements, Office of the Vice President for Research guidance, and MHealth Fairview and Medical School guidance (if applicable) in response to the COVID-19 pandemic. While the IRB continues to review and approve research, the guidance takes precedence, meaning that some research activities, including enrollment of participants, may not take place at this time for certain types of research. All researchers should review the guidance often as it is updated frequently by the Human Research Protection Program.

EXEMPTION DETERMINATION

June 25, 2020

Susan O'Conner-Von

651-230-0890
ocon0025@umn.edu

Dear Susan O'Conner-Von:

On 6/25/2020, the IRB reviewed the following submission:

Type of Review:	Initial Study
Title of Study:	Long-term care nurses' experiences with EOL care communication with patients and families
Investigator:	Susan O'Conner-Von
IRB ID:	STUDY00009947
Sponsored Funding:	None
Grant ID/Con Number:	None
Internal UMN Funding:	None
Fund Management Outside University:	None
IND, IDE, or HDE:	None
Documents Reviewed with this Submission:	• HRP-587 - TEMPLATE, Category: Consent Form; • Dissertation Study Flyer, Category: Recruitment

	Materials; • Interview Questions for Nurses in Long-Term Care, Category: Other; • Tealwood signed letter support PhD Dissertation 10-8-19, Category: Letters of Support / Approvals (Location); • HRP-580 - SOCIAL TEMPLATE PROTOCOL, Category: IRB Protocol;

The IRB determined that this study meets the criteria for exemption from IRB review. To arrive at this determination, the IRB used "WORKSHEET: Exemption (HRP-312)." If you have any questions about this determination, please review that Worksheet in the HRPP Toolkit Library and contact the IRB office if needed.

This study met the following category for exemption:

- (2) Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) as the following criteria are met: (i) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects (ii) Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation

Ongoing IRB review and approval for this study is not required; however, this determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these activities impact the exempt determination, please submit a Modification to the IRB for a determination.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the HRPP Toolkit Library on the IRB website.

For grant certification purposes, you will need these dates and the Assurance of Compliance number which is FWA00000312 (Fairview Health Systems Research FWA00000325, Gillette Children's Specialty Healthcare FWA00004003).

Sincerely,

Jeffery Perkey, CIP, MLS
Senior IRB Analyst

UNIVERSITY OF MINNESOTA

Twin Cities Campus

Human Research Protection Program
Office of the Vice President for Research

Room 350-2
McNamara Alumni Center
200 Oak Street S.E.
Minneapolis, MN 55455

612-626-5654
irb@umn.edu
https://research.umn.edu/units/irb

ACKNOWLEDGMENT OF MODIFICATION

July 20, 2020

Susan O'Conner-Von

651-230-0890
ocon0025@umn.edu

Dear Susan O'Conner-Von:

On 7/20/2020, the IRB reviewed the following submission:

Type of Review:	Modification
Title of Study:	Long-term care nurses' experiences with EOL care communication with patients and families
Title of Submission	Modification #1 for Study Long-term care nurses' experiences with EOL care communication
Investigator:	Susan O'Conner-Von
IRB ID:	STUDY00009947
Submission ID	MOD00018750
Sponsored Funding:	None
Grant ID/Con Number:	None
Internal UMN Funding:	None
Fund Management Outside University:	None
IND, IDE, or HDE:	None
Documents Reviewed with this Submission:	All revised study materials with this submission.

Modifications/updates included:

Per IRB submission, revision of Dissertation Study Flyer to identify that interviews will only occur remotely via secure U of MN Zoom videoconferencing and clarification that investigators will be conducting interviews via ZOOM and confirm we are using the

University of Minnesota secure ZOOM software to assure privacy and confidentiality for participants

This study continues to meet the following category for exemption:

• (2) Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met: (ii) Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation

• (2) Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met: (i) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects

Ongoing IRB review and approval for this study is not required; however, this determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these activities impact the exempt determination, please submit a Modification to the IRB for a determination.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the HRPP Toolkit Library on the IRB website.

For grant certification purposes, you will need these dates and the Assurance of Compliance number which is FWA00000312 (Fairview Health Systems Research FWA00000325, Gillette Children's Specialty Healthcare FWA00004003).

IMPORTANT: All human research conducted at the University of Minnesota must adhere to the IRB guidance and requirements, Office of the Vice President for Research guidance, and MHealth Fairview and Medical School guidance (if applicable) in response to the COVID-19 pandemic. While the IRB continues to review and approve research, the guidance takes precedence, meaning that some research activities, including enrollment of participants, may not take place at this time for certain types of research. All researchers should review the guidance often as it is updated frequently by the Human Research Protection Program.

Sincerely,

Bri Warner
IRB Analyst

Appendix G – Protection of Human Subjects

Protection of Human Subjects

Human Subject Research Exemption Qualification:
This proposed study meets the criteria of research that is exempt under paragraph (d)(2)(i) for 45 CFR Part 46 because it only includes interview procedures interactions in which all participant information recorded by the investigator will be deidentified and each participant's identity could not readily be ascertained or linked to them.

Research Description
Human Subject Involvement and Characteristics:
In order to investigate long-term care nurses' experience of communicating with patients, families and surrogates about end-of-life care preferences and choices through interviews, we plan to enroll those long-term care nurses' who meet study inclusion criteria.
Inclusion Criteria - Participants must meet the following criteria for inclusion in the study:

- Age ≥ 21 years
- Have < 2 years of long-term care nursing experience
- Be registered or baccalaureate-prepared nurses
- Be ≥ 0.5 FTE employees of Tealwood Senior Living long-term care facilities
- Be able to participate in at least one 90-minute interview with Principal Investigator (PI)
- Be willing to discuss their experience communicating with patients and families about end-of-life care planning
- Be able to speak and read English
- Be able to provide informed consent for study participation

Exclusion Criteria - Participants will be excluded from the study if they have:

- Have ≤ 2 years of long-term care nursing experience
- Are ≤ 0.5 FTE employees of Tealwood Senior Living long-term care facilities

Long-term care nurses play a critical role in care planning and goals of care communication for many long-term care patients. They are often the healthcare professional who initiates and sustains end-of-life care discussions with patients and families and they form significant relationships with patients, families or surrogates over the months and years between admission and discharge or death. The efficacy of end-of-life care planning interventions in long-term care is associated with nurses' accumulated experience and willingness to initiate these discussions. Qualitative phenomenologically-based interviews are the most appropriate methodology for learning experienced long-term care nurses process for initiating and sustaining end-of-life care discussions with seriously, or terminally ill patients, their families or surrogate decision-makers.

Role of Collaborating Sites:
The supporting partner for this study is Tealwood Senior Living (Tealwood) is a private Minnesota-based LTC organization that owns or manages more than 20 LTC facilities. Tealwood will support participant recruitment, enrollment and interviews. Approval from the University of Minnesota Institutional Review Board (IRB) will be obtained.

Description and Justification of Research Procedures:
Interviews with experienced long-term care nurses are the chosen data source of because they have developed knowledge of nurse-patient communication about end-of-life care choices and preferences through their accumulated practice. Thus, they have valuable insights about successful communication strategies that increase the likelihood of goal-concordant, patient-centered end-of-life care. Interpretive phenomenological interviews with nurse participants will describe their experience with this communication, including their intent, motivation and meaning, all crucial to understanding their decision-making process. Each interview will be

conducted by the PI, following interpretive phenomenological interviewing guidelines. Phenomenologically-based interview studies require an estimated sample of 10 participants to achieve qualitative thematic data saturation. Individual interviews of approximately 90 minutes each will be conducted at a convenient time for each participant either in a private room at their workplace to reduce potential distractions, burden and anxiety or via a secure teleconference. Interview rooms will be arranged, lit and furnished to create a calm, casual, warm environment. A modest financial token of appreciation would be offered to each participant to compensate them for their time. With IRB approval, the study protocol will include possible follow-up interviews with interviewees for clarification purposes, and the informed consent process will affirm participants' agreement.

Description of Research Material, Data, and Information to be Collected:
De-identified interview data collected includes participant background, experience, reason for becoming a nurse and interest in participating in this study. Question prompts will focus the interview on the phenomena of interest. The interviewer will also record reflexive journal notes after each interview and use these as part of the data analysis process. Participants will have the opportunity to review a summary of their transcribed interview to offer feedback, provide clarification on language and meaning, or stimulate additional contributions to interview data from their experience.

Management and Protection of Materials and Information:
Ongoing evaluation of completeness and accuracy of data collection will be completed by the PI will review all interview transcriptions to verify fidelity with audio recordings for quality assurance. Data will only be examined by the study PI. The PI, with consultation from the University of Minnesota School of Nursing, will oversee data management, including creating a codebook and collected data coding so data is in an appropriate form to be exported to qualitative software packages for analysis. PI will perform a weekly assessment of data entry problems and periodic data checks will assess if there is an indication of any systematic problems in coding or data entry. The security and integrity of all data will be ensured by restricting access to recordings and transcripts to the PI, according to the University of Minnesota School of Nursing's guidelines for protecting data privacy and stored on a University of Minnesota School of Nursing server, password protected and encrypted to protect study data.

Potential Risks to Subjects from Breach of Confidentiality:
There is little risk of breach of confidentiality since study participants will not be providing identifying information such as name, address, telephone number or date of birth.

Adequacy of Protection Against Risks
Recruitment & Description of Informed Consent Process:
Potential participants that meet eligibility criteria will be recruited electronically, emphasizing potential research benefits. Enrollment is either in-person or via secure teleconference to ensure participants' voluntary informed consent. Informed consent procedures include: (1) introducing the purpose of the study, the researcher/interviewer's background and affiliation with the University of Minnesota; (2) study protocol and procedures to assure participant confidentiality and safety, data integrity, and ethical guidelines; (3) and initial interview questions.

Methods to Minimize Risks of Breach of Confidentiality:
To minimize a breach of confidentiality, each study participant will be de-identified through assignment of a unique code name consisting of numbers and letters. Code names will be used for all data collection purposes, which will be kept in an electronic, password protected database

and only accessed by the PI. No identifying information will be provided in any files. Electronic data files will be stored on a secure University of Minnesota School of Nursing server that can only be accessed with a University login ID and password by individuals to whom the study PI has granted access.

Ensuring Necessary Medical/Professional Intervention for Adverse Events:
There is very low, or no risk of necessary medical interventions associated with qualitative interviews of medical clinicians. The subjects are all experienced registered nurses. PI will follow all relevant facility safety precautions in the event that medical intervention is necessary for adverse events.

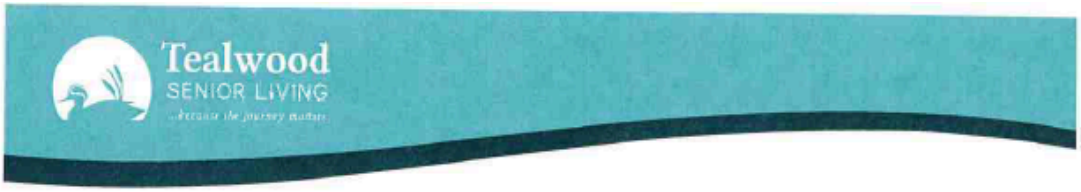
Importance of the Knowledge to be Gained:
This research is significant because communication about end-of-life care planning with long-term care patients, families and surrogates is challenging for all nurses and clinicians to initiate and sustain. However, this planning is important to goal-concordant end-of-life care, which increases the probability of achieving patient-centered care outcomes. Long-term care nurses face multiple barriers to communication about end-of-life care planning. The gap between long-term care nurses' identified need for end-of-life care communication and their demonstrated lack of capacity to engage in it has significant consequences, negatively impacting patients' quality of care, patient care satisfaction and nurses' work satisfaction. There is a current, pressing need to understand the process experienced end-of-life nurses use to initiate and sustain end-of-life care communication with patients, their families or surrogate decision-makers. Explicating their facilitators will support the design of end-of-life care communication training interventions for end-of-life nurses, and increase the probability that patients receive goal-concordant end-of-life care.

Potential Benefits:
The results of this study will provide valuable information to shape future nursing education and policies in long-term care, as well as improve the efficacy of current communication interventions nurses employ with patients and families to ascertain and document patients' end-of-life care goals and preferences.

Data Safety Monitoring Plan:
The proposed research is not a clinical trial. See Description of Research Material, Data, and Information to be Collected and Management and Protection of Materials and Information for information on protection of collected data and data files.

Inclusion of Women, Minorities & Children:
We will actively seek to enroll women and members of minority groups in the proposed study. Women represent the largest majority of the long-term care nursing population in general, and in Tealwood Senior Living's Minnesota facilities in particular. Thus, including women in this study should not present an issue.
Minnesota's population is approximately 79% Caucasian, but minority populations are represented amongst Tealwood nursing staff. Given an estimated study sample size of 10 participants, it is unknown what percentage of enrolled nurse participants will be members of minority populations. All minority nurses who meet initial eligibility criteria will be approached for study participation. Voluntary consent forms will be written in plain language to allow nurse participants of all backgrounds to easily read and understand its content. Using these strategies, we fully anticipate being able to enroll nurse participants of minority groups. The research topic to be studied is not relevant to children and we will exclude individuals younger than 21 years of age.

APPENDIX H – Tealwood Dissertation Study Letter of Support



October 2, 2019

To: Frank Bennett

RE: Letter of Support for Individual Interview Study

Dear Mr. Bennett,

I appreciate your current studies and understand you are now working on your dissertation study. This study would include individual interviews based on a phenomenological interview methodology with nurses about their experiences communicating with long-term care patients/residents and their families and surrogates about end-of-life care planning. The study would involve individual interviews of approximately eight to twelve nurses asking them about their experience. The nurses would be registered nurses or baccalaureate prepared nurses with at least three years of long term care experience. We serve both skilled facilities and assisted living communities with memory care and would have nurses from both settings available for your study if you would like. As you know, I have focused my work in this area of having these discussions and honoring individual choice for the past few years. It is an area that needs much more work and others will benefit from your study. I applaud your focus in this area and you have my full support and I look forward to helping in anyway I can.

Sincerely,

Gail Sheridan

Gail Sheridan, Chief Clinical Operations Officer

APPENDIX I – Healio *Journal of Gerontological Nursing* Embargo

Slack Incorporated Scholarly Uses of Journal Articles publication embargo policy: https://journals.healio.com/journal/jgn/submit-an-article

SCHOLARLY USES OF NON-OPEN ACCESS JOURNAL ARTICLES

Scholarly Use	Abstract, Link to Article on Healio.com, and Citation	Author's Accepted Version	Final Publisher Version
Author's personal, noncommerical website or blog	Yes	Yes, 12 months following publication	No
Author's promotion/tenure packet	Yes	Yes	Yes
Sharing with colleagues on request for their personal use	Yes	Yes	Yes, authors may share their complimentary access link (which allows 50 free PDF downloads) with colleagues but may NOT distribute the link to large email lists
Teaching/training at the author's institution	Yes	Yes	Yes, as long as reasonable measures taken not to allow open sharing on the internet
Conferences (oral presentation, display, and/or photocopies)	Yes	Yes	Yes, up to 25 print copies may be requested (contact the editorial office if more are needed)
Dissertations, theses, or grant applications	Yes	Yes	Yes, with the exception of open access theses/dissertations
Institutional repository (private, closed)	Yes	Yes	No
Institutional repository (open access)	Yes	Yes, 12 months following publication	No
Funding repository (including the National Institutes of Health)	Yes	Yes, 12 months following publication	No
Scholarly collaboration networks (eg, ResearchGate, Academia.edu, Mendeley)	Yes	Yes, 12 months following publication	No
Social media	Yes	No	No
Commercial purposes	Contact the publisher	Contact the publisher	Contact the publisher

Journal of Gerontological Nursing applies a 12-month publishing embargo on accepted manuscripts. Posting of this dissertation to an institutional or subject repository, or to a scholarly collaboration network will be postponed until 12 months following publication of Chapter 2 in *Journal of Gerontological Nursing.*